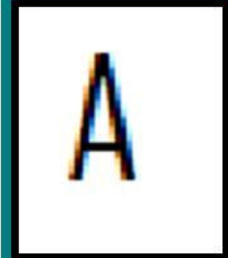

Listen to patients, Speak up for change

INSIDE FRONT COVER

'How people die remains in the memory of those who live on'

Dame Cicely Saunders

With thanks to the many people who kindly volunteered to take part in this project for the benefit of others, and thanks also for the many others that contacted us but unfortunately couldn't be included. Everyone's experience is valued, published or otherwise, and all contributions are gratefully received.

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SPACE

FOREWORD

Claire Rayner OBE, 22 January 1931 - 11 October 2010

In the last, difficult months of her life my mother, Patients Association president Claire Rayner, received some truly exemplary care. For the most part Claire, who died in October 2010, was looked after with true compassion and consideration. But there were times when things went wrong: when her nursing was assigned to agency staff who knew little or nothing about her and made absolutely no effort to find out, when calls for assistance went unanswered, when doctors treated her less as a person than as a set of conditions and readings on a chart. She found this hugely distressing, but it also made her very angry. As she said time and again if even she, with her public profile, reputation for straight talking and acute knowledge of the mechanics of nursing and medicine could not get the treatment she was entitled to what hope was there for others?

Indeed. If she had been alive today my mother would have been infuriated by the distressing accounts of poor nursing and medical care experienced by older people, contained in this very important report. Claire was never one for blanket statements and would have been the first to point out that many nurses and doctors are hugely considerate in the way they deal with older patients, who may be confused, distressed or simply frightened by the situation in which they find themselves. The positive comments at the front of this report, made by relatives of those whose stories are told here, attest to that. But any health system is only as good as its failings, and those detailed in these pages are truly dismal. The Patients Association makes absolutely no apologies for the fact that this document will prove very difficult reading.

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But it must be read. The lessons must be learned. Claire was a passionate believer in advocacy on behalf of those who could not make themselves heard, which was why she dedicated so much of her later life to the Patients Association, and the absolutely vital work it does for those striving to receive the quality of care to which they are entitled. If she were here today she would have been hollering from the roof tops about it, berating politicians, health service managers and medical professionals alike. Instead it is the stories of older patients and their relatives themselves that must be listened to. And not just listened to but acted upon. Claire Rayner would have accepted nothing less.

Jay Rayner

INTRODUCTION

The aim of this report is the same as last years. We are seeking to amplify the voices of those individuals that have so courageously shared their stories with us. We want these stories to be read across the NHS and Government.

We have based the title of this year's report on the motto of our organisation: listening to patients, speaking up for change. This was the mission to which Claire Rayner dedicated herself. But it is also what the rest of the NHS needs to do. All staff need to listen to patients, and where patients are being let down, staff need to speak up for change. But patients and the public need to speak up for change as well.

Last year when the Patients Association published *Patients not numbers, People not statistics* we were overwhelmed by the response. Over 1,000 people contacted us to say that they had experienced or witnessed firsthand the kinds of failings in care described in the report. Many of these people felt hugely reassured by the knowledge that they were not alone in their experiences.

Some of coverage of the report last year focused on whether or not the problems highlighted were 'representative'. Profound apologies were given, the examples published condemned, but statistics evidencing how many millions of patients are happy with their care were put forward as some kind of answer to the problem we were presenting. Writing in the Health Service Journal, Ken Jarrold asked:

"Exactly how many times is it acceptable for a patient to be "left in their own faeces and urine" until relatives ask for them to be changed? How often should a patient be told that "because of being unable to use the toilet… she should wet the bed"? Is that OK as long as it is only 10 times a month or 20? How many times is it satisfactory for night staff to squeal and giggle while confused patients wander around semi naked and staff pass them in the corridor without a care?

"It is no defence to claim these are rare events or that most patients are happy. These things should never happen. Any health service can be forgiven for wrong diagnosis in complex cases or the inability to treat because of a genuine shortage of resources. No health service should be forgiven for wilful neglect of the most basic aspects of cleanliness and dignity."

However, in an environment when numerous important issues compete for the attention of policy makers, it is important to evidence that these kinds of stories are not just one offs, though unacceptable no matter how rare.

We stand by the figures cited in the report last year, based on the findings of the national inpatient survey. Every year (maintained in the results of the latest survey) around 2% of inpatients surveyed rated their care as poor. This could equate to over 1 million patients over the course of the years the survey had run at the time we published our report. We have never claimed these figures to be absolute. Our intention was simply to highlight that if a service is delivered to millions of patients every year, substandard care being given to even a small percentage equates to very large numbers of people.

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There is very little comparable evidence collected about the experiences of patients like those contained in this and the last report. The vast majority of the patients featured either passed away during or shortly after their time in hospital, making it extremely unlikely that they would have taken part in the national inpatient survey. Some of the patients whose experiences of care we have highlighted lack the capacity to complete feedback surveys.

Published after our report the Alzheimer's Society research *Counting the cost*: *Caring for people with dementia on hospital wards (Nov 2009)* used the solution of asking carers to rate the care of those they cared for. This survey of over a 1,000 carers of patients with dementia admitted to hospital found only 23% were satisfied with the help given to eat and drink, only 30% were satisfied with the help given with continence needs and only 32% were satisfied with the help given with personal hygiene. Those figures are extremely worrying. Despite its weakness the national inpatient survey has found similar results for many years in respect of help being given to patients when eating.

As well as concerns about the quality of care given to their relatives, many of the writers of this year's stories join last year's in being extremely dissatisfied with the NHS complaints process. The aforementioned Alzheimer's Society survey found only 7% of people that complained were happy with the outcome. Another concerning finding.

The Mid Staffordshire Public Inquiry currently being conducted by Robert Francis QC may provide an excellent forum for a comprehensive assessment of the systems of regulation, supervision and performance management of organisations and staff that should ensure that the kinds of problems highlighted in this report are almost non-existent. But this will be unlikely to deliver its recommendations until the summer.

The current White Paper proposals put forward ideas and themes, particularly around the collection and publication of patient experience information, which may help to address this apparently intractable problem. But it is not good enough to wait.

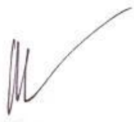
The new Government must act *now* to ensure every patient receives the essentials of nursing care when in hospital. It is the very least every patient can expect. These stories highlight just how terribly the lives of patients and their families are affected when these essentials are not given.

The investigation of the failings at Mid Staffordshire NHS Foundation Trust revealed just how difficult it is to pick up on poor care, even when it is widespread. The cases we hear about on our Helpline are from across the NHS and the results of the Alzheimer's Society survey also suggest the magnitude of the problem. We believe a fundamentally new approach to the problem is required and propose the permanent presence of independent monitoring based within each Trust to address these issues. These 'patient safeguarding champions' would not be monitoring each and every aspect of hospital care but would focus on the essential standards of nursing care that every patient should expect and serious patient safety concerns. Ideally this role would be filled by a clinician who can confidently monitor these standards. We would like this approach to be piloted and evaluated urgently for wider introduction should the model prove successful.

Last year we made a number of separate recommendations around complaints handling. As the cases we have heard about on our Helpline and the recent report by the Parliamentary Health Service Ombudsman have shown, the system is still not working and must be completely reviewed.

In the interim a national survey should be introduced for all complainants to allow a better understanding of which Trusts are providing a good complaints process and which ones aren't.

The Department of Health should consider how surveys of the carers of inpatients can be conducted nationally, similar to the survey conducted by the Alzheimer's Society survey. We believe the results of such a survey would provide a unique and important insight into the quality of care at Trusts.



Kieran Mullan

The Patients Association

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CALL TO ACTION

The Department of Health, in partnership with a suitable independent body such as a local authority or the Care Quality Commission, should instigate the establishment of a pilot to introduce independent clinical 'patient safeguarding champions' at a number of individual Trusts

The Department of Health should conduct a comprehensive review of the NHS complaints process. In the interim a national survey should be introduced for all complainants to allow a better understanding of which Trusts are providing a good complaints process and which ones aren't.

The Department of Health should consider how surveys of the carers of inpatients can be conducted nationally, similar to the survey conducted by the Alzheimer's Society.

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POSITIVE COMMENTS

"The treatment she received whilst in the Care Home was exemplary. The team there and the district nurse team did all they possibly could to ease her pain and improve her condition and they deserve the highest praise for their care, professionalism and compassion." Elin styles

"All the staff at the care home were extremely kind and welcoming to Mum and to us, and have been enormously supportive during this difficult time." Liz Pryor

"I was admitted to an assessment ward and had excellent treatment there. I can't thank enough the staff nurse for taking me through a crisis. I am also grateful to the other staff who were there as needed in a very busy ward with lots going on. The staff nurse kindly came to see me before she went off shift, to say that I would probably be transferred to another ward, so I probably would not see her again. A very nice and important touch." Brigid Wainwright

"We had had contact with the Royal Devon and Exeter hospital for over 20 years and when he first attended there he had what can only be described as 5 treatment with fantastic care at all times. His life was saved several times."* Margaret Clarke

"Firstly I would like to praise and thank the many wonderful nursing staff, physiotherapists and doctors that have helped with the care of my husband David J Perkins. He had previously been at Southend Hospital in February and March for chemotherapy where the staff had been extremely kind and courteous." Maureen Perkins

"Besides when she was having children my mother has only ever been in hospital once before… She tells us that the care then was wonderful." Carole Brown

"The surgical team was great and Mum's operation was completed without incident." Heather Donvoan

"After 4 weeks she was transferred to a care facility for rehabilitation, again under the auspices of the NHS, but there the situation was totally different. The staff were caring and thoughtful." Susan Mistry

1. Peggy May Wood

By her Daughter-in-law Elin Styles

My Mother-in-Law, Peggy May Wood passed away on 22nd December 2009. Since March of that year she moved frequently between her Care Home and Southend University Hospital. The treatment she received whilst in the Care Home was exemplary. The team there and the district nurse team did all they possibly could to ease her pain and improve her condition and they deserve the highest praise for their care, professionalism and compassion.

During the times Peggy was in Southend University Hospital I was utterly appalled at the so called "care" she was given. Peggy developed a bed sore during her first admission in March and every time she returned care of this terrible condition was all but absent. In the end, our family fought terribly hard to prevent her from being readmitted as we knew entering the hospital was certain to just add to her suffering.

Peggy lived alone in her bungalow and despite her disability, she had coped very well for many years. We then started to notice that things were not quite right. The house was becoming untidy and she started to seem confused at times and a couple of times had what we later realised was hallucinations which must have been very frightening for her. We also then discovered that she was not taking her medications properly and found tablets in the most unlikely places. She was assessed by the Mental Health Team and found to be in the early stages of Dementia.

It was decided that some help in the home was needed and it was arranged by Social Services but paid for by my mother-in-law. I was told that this means that my mother-in-law was having private care as she was paying for it herself, out of her savings. This apparently also meant that she was not

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entitled to any support from Social Services. Try as I may I cannot understand how this is deemed to be fair. If she had no money at all, she would be entitled to help.

As we live over 100 miles away, we could not provide help on a daily basis, although over a long period I went down to see her a couple of times a week. It was very difficult to persuade her to have help and the first company we found proved to be quite unreliable and never really did what was required of them. As Peggy had a vast amount of tablets to take each day, I had managed to organise that they were given to her in blister packs but they proved to be a problem for her too. It should however, not be a problem for a carer but it was. It was quite clear when I came down to see her that she was still not getting her medication regularly.

One day Peggy called around lunchtime and said that the "lady" had not come and she was still sitting in her nightie. We called the care company and was told that they had been and had helped Peggy to dress and given her breakfast, tablets etc. I then called Peggy back and spoke to her about it but she was adamant. I called the company back to try to get to the bottom of it. The woman I spoke to said that the carer who had been to Peggy was standing next to her and was telling her that she had definitely been and had spoken to the neighbour in number 12, I think it was, who was outside washing his car. She had dressed Peggy in her favourite purple dress and given her breakfast. She also commented that Peggy seemed very confused, the dog wasn't there and she had not been able to find the notes to write anything down. I then got slightly suspicious as Peggy lived in number 2 - the neighbour was number 4, Peggy never wore purple and the dog never left her sight. It turned out after some detective work that the carer had gone to the wrong address, dressed the wrong lady who did not have a dog, was not called Peggy and did not normally have a carer. It was almost amusing it was so preposterous, but it really is a worry to think that such a big mistake could be made.

We spoke to Social Services about these problems and were given an alternative.

Peggy was first admitted when I visited her at home and found she was dehydrated and unwell. She had Dementia and was clearly not coping living alone. No transport was available, so I took her to the hospital in my car. On arrival, I had no idea where to go, only the name of a ward and I had to abandon her and the car near the Ambulance Station in order to enter the Hospital to find out where to take her. I managed to speak to an elderly volunteer seated in the foyer and was told to go to Casualty. But no-one offered to help.

At Casualty we had to wait and be signed in, in a queue. I managed to find something resembling a wheelchair which my mother-in-law perched on whilst I waited to sign her in. Part of her disability is that she cannot bend her legs and therefore needs some sort of support in order to be comfortable. Since she was at the Hospital to be admitted she was obviously not feeling at all well, which made it even more uncomfortable. I was then told to take her to the ward along the corridor. At the ward, we were told to wait again. My mother-in-law was still sitting very uncomfortably in this cross between a wheelchair and a trolley with her legs protruding.

We were then shown into a very small room, containing a couch, desk and medical equipment. I managed to get the chair into the room and various nurses etc. then started entering. Only one, out of the 3, 4 or even 5 different people who were in and out of the room, actually managed to acknowledge the person in the wheelchair, my mother-in-law, and say hello. I was asked some

questions but she was just ignored, in the chair, still with her very fragile legs sticking out, visibly shaking with cold and feeling dreadful.

The nurses tried with no success to read her oxygen levels but the finger clip was not working. Without saying a word to her, they were attaching the clip to her ears and various other places. No explanations or reassurances. They then attached pads to various parts of her body in order to get a reading. Again, without speaking to her, her clothes were pulled and pushed, including her jumper and bra, which was pulled up around her throat. When this was completed, she was left sitting like that, still shaking because she was feeling cold. Yet another person then bent across her to take a blood test from her arm.

There was not enough room for the person to stand at the same side as the arm she was taking the blood from. My mother-in-law was then told: "You are just going to have to sit still, or I cannot do this." I wonder how many young able bodied people would be able to sit still in that position.

At this point I asked everyone to stop and calmly pointed out that she was a human being and there because she was not well and requested that she might be allowed at least the dignity of being dressed again and made as comfortable as possible. This did have some effect but she, or anyone else for that matter, should never have been treated in such a way. It was unbelievably undignified and certainly not caring in any way.

She was later given a bed and made much more comfortable but mainly by myself as staff was busy elsewhere.

Early the next morning she was transferred to the Southbourne Ward where she was treated for the dehydration and infection.

She had treatment and the infection cleared up quickly, so by the end of the first week we were told that she was medically fit to go home but would need a more extensive care package, which would be organised. As the confusion had not improved as a result of the treatment, we requested a more comprehensible mental health assessment, which was agreed.

I received numerous telephone calls regarding my mother-in-law and her care from various members of different "Teams" involved in her so-called care. One of the first, from the "Rehab" Team included the sentence: "She seems to have a problem bending her knees, do you know why?" She has been disabled for over twenty years and apart from it being quite obvious as her knees are much scarred, it must also be in her medical notes and I have pointed out that fact several times. –It would also perhaps have been an idea to ask her.

I also tried to explain countless times the fact that the disability is catered for in the home, has not worsened and is not the cause of the problem. The problem was that my mother-in-law is becoming increasingly confused and losing her memory, which means that she is no longer capable of some simple tasks like eating properly, drinking enough and taking care of her own personal needs.

Suggested by the "Rehab" team, a meeting was arranged at the hospital, to be attended by all parties involved in order to decide what to do to in order to secure the best possible care for the future. My husband and his brother attended, hoping that some conclusion would be reached.

Approximately one hour before this meeting was due to take place, I received a call from a social worker attached to the hospital. She introduced herself and continued: "I have been asked to attend a meeting at Southend Hospital today. Do you know what it's about?" I obviously thought I must have misunderstood her but she repeated the question. I had to explain to her what the meeting was about. Goodness knows what would happen if someone didn't have a relative or carer to do this.

It appeared that she did not attend the meeting but sent one of her assistants who asked my husband whether his mother pays for her own care. He confirmed this and was told that in that case it has nothing to do with them (the social workers). The meeting did not come to any conclusions. So this was in effect a pointless 200 mile round trip.

At the beginning of the third week, it was suggested that a home visit should be arranged to assess how my mother-in-law copes in the home but as it would be unlikely that she would agree to then go back to the hospital, it was agreed it would be too upsetting for her. The "Rehab" team then met me at the property in order to assess the home and write a report with recommendations for future care.

I was told that my mother-in-law was no longer able to walk and had to have two carers to help her transfer between her bed and chair and as a result would have to effectively stay in one room in the home. I was quite shocked by this as she was capable of walking by her walking frame albeit quite slowly, before she went into hospital. I accepted this as the case as I had not seen her out of bed in the ward and I assumed that they had all the information needed to make this assessment. The team then went back to the hospital in their booked taxi and I drove there in my car. One of the team was at the nurses' station as I entered the ward. Towards us came my mother-in-law walking with a frame!!

Two days later I received a call telling me that she is now walking and therefore is ready to go home.

A mental health assessment by a psychiatrist had still not happened and was requested again. I called the local health centre where my mother–in-law is already known and they were more than happy to come and assess her but needed to be contacted by the hospital in order to do so. This finally happened after over 3 week's stay in the hospital. The staff I spoke to at the local health centre was very helpful and understanding.

I was then contacted by a social worker from the hospital on the 4th week of the admission. At the time I was on my way to my mother-in-law's property to meet the "rehab" team who I was told needed another home visit, which had been arranged for that day but no exact time had been confirmed. No-one turned up and when I called to enquire, no-one knew who had been due to visit. Yet another pointless 200 mile journey.

I met with the social worker in the Southbourne Ward and having tried to explain my frustrations I was told that actually because the care was paid for privately she had been told by her manager not to get involved. She had been shown a "Care Package" which we had been emailed a couple of days before, by the Discharge Nurse and after speaking to me on the telephone had realised that my mother-in-law does not need 2 carers 4 times per day as she is capable of walking by her walking

frame. Thus she had changed the 2 into a 1 on the form. She also suggested that a team of carers could come to the house and assess over a period of 4 weeks.

So consequently, after having assessments, reports and more assessments done during nearly 5 weeks in hospital, my mother-in-law was still in the same position as she was. No doubt there are assessment results and reports in her file but in reality, nothing was achieved, no real support has been given by any of the professionals. Not what I consider to be care in the community.

I finally realised that nothing was going to happen unless we did it ourselves, so I told the relevant staff that I would be taking my mother-in-law home on Monday 23rd March. In the meantime I organised the care, medication, food and everything else she needed in order to be as safe, well and happy as possible. She was still as confused and her short term memory was still the same. She was still having hallucinations of varying degrees.

I arrived at the Southbourne Ward mid-morning (having again spent 45 minutes queuing to park) and found my mother-in-law dressed and packed. I went to the nurses' station and spoke to the Staff Nurse who found me a pack of incontinence pads to take home. They only had the large size and my mother-in-law is a size 12 and uses a medium. I spoke with the nurse about medication and told her, as I had told the "Rehab" team etc. when I said I would organise everything myself, that I had sorted it all out with the local chemist and did not need any medication to take home. When I later unpacked everything, what did I find - a bag of medication but only about half of the various tablets. According to the accompanying notes I could get the rest at the pharmacy. Whether this means the hospital pharmacy or local pharmacy, I don't know. I brought my mother-in-law's own wheelchair and we left. No one offered any help or even noticed that we left. Luckily I had managed to park in a disabled space in the car park so we had enough room to be able to get into the car etc.

I cannot even remember all the conversations and calls we had during this month or so, all of them achieving nothing. Individually, there are some very nice, caring people working in Southend Hospital, but there is no communication, no follow up of anything and no sense. The system, presumably designed with caring for people in mind is totally shambolic and completely unacceptable. Had it just been one or two incidents, it could be put down to experience but the whole picture is beyond belief.

Within a week of her being at home it was clear that Peggy was still not able to cope even with help. We managed to find an excellent local Care Home for her in the beginning of April. On arrival at the care home, Peggy was assessed by the GP and found to have a small red mark at the bottom of her spine. She was immediately given an air mattress and the red spot was treated every day to prevent a bedsore developing. She also had a small chest infection which developed very quickly and she was admitted to Southend University Hospital on 10th April.

The ward was full of elderly people in the same situation and stank of faeces. I never once saw anyone being helped with food or drink. Common sense tells you that lack of food and in particular drink causes dehydration which has a huge impact on your general health and things like bed sores.

She was always covered in food matter of one sort or the other and in varying degrees of dryness during her stays in the hospital and on many occasions I would ask the staff for a clean nightdress, to

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be told that someone would change her as soon as possible and end up trying to do it myself. As a rule I would check if she was clean and dry on arrival at the hospital and that was very rarely the case either and I would again have to ask several times and end up having to be quite firm, bordering rude to get results.

The bed charts which amongst other things should be recording the times she was turned to ease the pressure on the bedsore were never complete. When questioned, the answer was universal: She will have been moved but the staff are so busy they don't always have time to record it. Turning the patient is an essential part of the treatment of a bedsore.

On arrival back at the care home on 26th April having spent just over two weeks in Southend University Hospital she had developed a serious bed sore at the bottom of her spine. Due to the position of the bed sore she was now bedbound and continued to be so until her death. Her condition was reported to Protection of Vulnerable Adults and The Tissue Viability Team by the care home staff. The sore was monitored and treated by the District Nurse Team every day but on the 6th of June it had become infected and she was admitted to Southend Hospital again for treatment. She was admitted for the same reason in October and November and on all three occasions I witnessed the same distressing failings in the care that I saw when Peggy first went into hospital in March.

We tried to get to speak to the consultant several times on her last admission but we were continually told that neither he nor any doctor responsible for her care was available. I managed to get to speak to him on 6th November as he happened to be doing rounds during visiting hours. I explained that we (the family) felt quite strongly that these continual hospital admissions were achieving nothing positive but were painful and upsetting for Mrs Wood and that we felt she should be left in peace. He wholeheartedly agreed with me and signed the discharge papers straight away. On that occasion it took 24 hours before transport was available.

Shortly after her return to the care home my husband and his brother made an appointment with her GP to discuss the future. They expressed the family's wishes of no more hospital admissions as it served no purpose but to upset and frighten her. They were told that they would have no say in this matter and that decisions would be made by the GP as and when. So, on 15th December after some discussion with both care home staff and family, the GP overruled what we felt was in Peggy's best interests and she was again admitted to Southend Hospital. The ambulance was called around 3 o'clock in the afternoon.

I understand that doctors must make decisions for their patients and that we cannot have the final say but we felt strongly that he really was not listening to us, her family, when making his decision. We, who loved and cared for Peggy, who knew her well and saw firsthand how much she hated being in hospital, are surely able to offer a very good insight into what is best for her and what she would've wanted?

I left straight away after receiving the telephone call and actually arrived at the hospital before the ambulance. This was at around 7 o'clock in the evening. As I feared, Peggy was terribly confused, upset and frightened as she had been on the last admissions.

After an hour or so a Doctor came in to assess her. She turned Peggy with the help of a nurse, to look at the sore and it was then evident that she had soiled herself quite badly. They laid her back as

before and left. Naively I assumed that the nurse would return quite quickly to clean her but that was not the case. After asking twice and waiting 30 minutes I helped one nurse who was willing to change her to turn her. A blood test was taken but apart from that no more contact with medical staff and no treatment. She was eventually moved into the Medical Assessment Ward and onto an air mattress just before 11pm. It was just after midnight when a Doctor was free to deal with Peggy. To my relief she was in full agreement with us as a family that continuing treatment was not humane and assured me that she would speak with the Consultant in the morning and she would be discharged.

She was true to her word, for which I am very grateful, and Peggy was taken back to the care home where we knew for certain that she was being cared for with compassion, understanding and dignity. We also knew that the bedsore would be treated and dressings changed every day by the District Nurses Team. Whilst in the care home Peggy was also turned as much as possible every couple of hours to relieve pressure. This was not the case in the Hospital. On one ward I spoke to a Ward Sister and pointed out that according to the care sheet in Peggy's folder she had not been turned more than twice that particular day and very little in the days prior. The response was again that the nurses don't always have time to record their actions.

I was with her on each admission and each time had to request an air mattress due to the bedsore, each time the same answer being that there are no air mattresses in A&E but she would be given one as soon as she was moved into the Medical Assessment Ward. On one occasion this was nearly **7 hours.** Even a short time on a hard mattress can cause untold damage to a bedsore and especially on one as severe as this was. She was left soiled, dirty and uncared for many times. This applies to any of the wards, not just A&E.

It is impossible to mention each incident of neglectful, uncaring and unthinking treatment in the hospital, though. One I will mention was when I walked through the door on one of the wards, just as Peggy was reaching for a hot cup of tea, placed on the side table within her reach. She was lying down and shaking as a leaf at the time. I ran to retract the cup, brought it to the attention of a nurse and was told that the tea lady was temporary. When she was approached by the nurse, asking her why she gave Peggy a cup and saucer she said: "I asked the lady if she wanted it". –She clearly had not been briefed by ward staff despite the ward being full of people in the same situation and was unaware of the fact that her action could have caused untold damage and burns. I responded that had she asked her to go for a picnic on the moon as well, Peggy would've smiled and said yes to that too.

Judging by Peggy's night gowns, hands and bed linen when visiting, she rarely or never had help with feeding herself. She was covered in dirty marks from food and you could see clumps of dried food under her finger nails. This applies to all wards she was in, sadly not just one ward. I cannot bear to think what went on outside visiting times.

The day before Peggy passed away, she was "seen" by a GP from the local surgery. She recommended no further treatment. The same GP was then called on the following day, to certify the death. The cause of death is recorded as: "Old age and infected lesion on leg". The bedsore which consequently caused her death was at the bottom of her spine. She had no sores or lesions on her legs. When I called the Dr and questioned this, she told me that 1) She was told by staff at the

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care home that the sore was on Peggy's leg and 2) That she had seen the bandage but not the actual bedsore. As every member of staff at the care home was involved with her care, I am absolutely certain that that was untrue. I did ask them and spoke to the person who was dealing with the GP when she attended which just confirmed my thoughts. Secondly, I would expect that a qualified Doctor would be able to distinguish between the bottom of a spine and a leg.

So, even in death, there was no respect or care from the NHS.

The response to my initial letter was a letter of apologies in varying degrees and the offer of £50.00 towards a wasted journey. I expected the apologies and did not really harbour any hope that there would be any changes. The offer of money I regard as an insult!

The Tissue Viability Team at Southend Hospital was made aware of the bedsore in April. I personally spoke to the lead nurse Richard Conway who told me that he was investigating and would let me know his findings in a couple of weeks from then. I heard nothing from him and no action was taken by him or the team. I contacted him on 12th January 2010 and received no real response or reaction. He is "refreshing his memory" but I do not expect to hear from him.

Peggy Wood suffered lots of illness through her life which left her disabled but always coped with a smile and tenacity. She always took great care of herself and was beautifully dressed and presented. She was a very well loved lady, not just by her immediate family but by her many friends too. To watch her decline due to dementia was upsetting enough for everyone but to have to spend her last months bedridden and consequently isolated from activities, interactions, outings etc. due to pure neglect in a hospital where one would and should expect care and quality nursing, was devastating. She must have been in horrific pain. Sadly nothing can help her now but she was unbelievably just one of so, so many. This cannot possibly continue to happen to elderly vulnerable people who, when dementia is also present, in effect lose their voices and ability to speak up for themselves. Someone must speak up for them. Please.

2. Anne Robson

By her youngest daughter, Liz Pryor

My mother was a gentle natured woman whose life revolved around her family. She was very proud of her five children, and adored her grandchildren. My parents had a very happy marriage and when my father died in 1989, Mum struggled to come to terms with life on her own. Even though she was very lonely she never complained. She enjoyed her dogs and her garden and was always careful with her appearance.

Mum had had a number of falls, which led to her having to have pins put in her hip last year. Unfortunately, the pain in her hip reduced her mobility dramatically, and after having the pins removed in August 2009, she was unable to mobilise at all, and therefore could no longer be looked after by a carer at home. She moved to a care home, where she lived until she died in January 2010. In the weeks before she was admitted to West Suffolk Hospital, she had been in particularly good spirits. She had just spent her first Christmas in the nursing home, a prospect that she was not looking forward to. However, she very much enjoyed herself, and was really beginning to settle down and make the most of life in residential care. The nursing staff were very fond of her, she had a naughty sense of humour and really enjoyed regaling them with stories about the family and her late husband. All the staff at the care home were extremely kind and welcoming to Mum and to us, and have been enormously supportive during this difficult time.

Early on the morning of Saturday 16th January 2010, Mum fell out of bed. Unfortunately she had always refused to have sides on her bed. I met Mum in the West Suffolk Hospital A&E department at approximately 9am that day - she had been there for about an hour and a half.

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The staff there didn't know anything about her. They didn't know her age, where she lived, whether she could walk etc. She was very confused. She had had x-rays and been seen by the registrar on duty. It was a difficult diagnosis as they did not at this stage have any x-rays from her previous surgery to compare the new ones with. She had not been given anything to drink and was very thirsty. During the course of the day, Mum was seen by a succession of doctors, some orthopaedics and some on-duty A&E doctors. They all spoke very quickly and she couldn't understand them. They did not make any concession whatsoever for this. However, during the course of the day, I think the shock of what had happened wore off a little, and we were able to chat and laugh about what was going on around us, and she happily sat up in bed and drank coffee and ate biscuits. The registrar then came and said that Mum had not broken anything, and that she would discharge her that afternoon. Within half an hour Mum was seen by one of the orthopaedic doctors and he said that he was concerned about the angle of Mum's right leg. (her feet made a right angle – i.e. her right heel was touching the instep of her left foot). Then another doctor came in, and said that they had decided that they would operate on Sunday morning, performing a partial hip replacement – even though they had still not seen the xrays from Ipswich.

One of the doctors completed the Medical Admission notes in the A&E Department. I was present when Mum was given what they call a Mini-mental test. This asks questions such as what is your age, what date was WW1, who is the Queen, can you count backwards from 10 - 1 etc. Mum found this test hard, and I remember feeling quite concerned that she only managed to answer three of the ten questions correctly. I was very surprised to see, when I received the Medical Records, that she was given 10/10 on her notes. What is the point of the test if the results are wrongly recorded? She had some more x-rays taken and then went up to the ward.

On arrival at the ward I was told to wait outside, having been assured by the nurse who came with us from A&E that I would be allowed to accompany mum on to the ward. I waited for about half an hour, and was then told, very briskly, that it was a "closed ward" and I would not be allowed in. The hospital had norovirus, and some wards were closed in order to try and reduce the spread of infection. I tried to explain that this would be extremely disconcerting for Mum as she knew I was there, and that I was very upset that the bed had been pushed through the doors with absolutely no thought towards my mother or myself. I was walking behind the bed. It would have taken no time to say a quick goodbye before they went into the ward, - and then their infection control would have been adhered to. As it was, I explained how upset this would make mum (and me) and the nurse conceded that I could go in quickly to say goodbye. Had I been less assertive, I would not have been able to say what I now know was my last goodbye to my mother.

This was the last time I saw my mother though I visited the hospital and spoke to her on the phone. All week I had to tell myself that everything would be ok, that of course the hospital were looking after her, despite the fact that over the phone and from talking to my sisters I knew she was deteriorating.

On Sunday morning, I called and spoke to staff on the ward and was told that no operation was going to happen, but that they were monitoring her pain - she was "not fit for theatre". We now know that this was incorrect. We requested Mum's medical notes after she died, and from them can see that the nurse had read them wrongly. The notes clearly state that Mum was seen by the

Orthopaedic Consultant at 8am that morning. He had her old x-rays from Ipswich, and her hip was not fractured. What the notes had actually said was "not for theatre", which is where the first major error occurred. Had we known Mum's hip was not fractured as early as Sunday, she could have been discharged before she got an upset tummy. As it was we were not given this vital information until the Tuesday afternoon, two days later - and by this time Mum had an upset tummy and was in an isolation room.

My sister Catherine went to the ward in the evening and was allowed onto the "Closed Ward" to see Mum. Catherine told me that Mum's nighty was wet up to her armpits. When Catherine asked the nurse if someone could come and sort it out the nurse was keen to say she had checked only half an hour ago. Catherine and I agreed that one wee would not make you wet to your armpits so goodness knows how long she had been like that. We also requested that the hospital use the "pull-up" pads that Mum used at home for her incontinence. They refused, saying that they only use the flat pads, as they are easier to change, and we had to take Mum's usual pads away. Essentially Mum was expected to go to the loo in her bed. The indignity of this makes me cry to this day.

On Monday I spoke to the ward sister again, who said Mum was comfortable, that she did have a fracture, but that she remained "not fit for theatre", so they were not going to operate. Once again when I asked why she was "not fit for theatre" I was told that they didn't have any further information on this (we know now that she had no further information because there wasn't any - her hip was NOT fractured, but yet again the notes were read wrongly - or not at all). She said that when sent home she would be bedridden, as her hip was very painful. I asked whether it was normal to send a patient home with a fractured hip. She proceeded to tell me…. "When they do this – we quite often sent them home and their quality of life is not good, but when they get that infirm it really is the only course of action open to us". I stopped her and asked her to remember that we were discussing "my Mother", and please could she not talk about Mum in that way. I found it very upsetting.

The conversation with the sister made me feel extremely annoyed so I tried to speak to someone in authority to find out exactly what was happening as the nursing staff did not seem to know. The reception informed me that I couldn't speak to a consultant or a doctor, but that I should speak to the beds manager who would be able to help me (which I thought was quite strange). I did speak to the beds manager and she told me that she would do all she could to help me find out what exactly was going on - she said she is very busy and if she couldn't help she would make sure someone else did, and that they would stay in touch with me. She seemed to be very concerned and helpful. I didn't hear back from her.

On Tuesday I rang the ward and spoke to the staff nurse. She said Mum had been moved to a side room during the night as she had had an "episode" of diarrhoea and they were worried that she had contracted norovirus. I asked them to explain the move clearly to Mum, and also to explain why she wasn't having any visitors. On the ward we had arranged for Mum to have a telephone - this was our only form of communication. We had put £10 credit on it and when I asked about this and what we should do about transferring it to the side room, I was told that it was just bad luck - that she would get a phone eventually in the side room, but that they couldn't transfer the credit. The hospital has

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since assured us that this is not their policy. The credit goes with the patient, not with the phone. Another example of management and front line staff doing and saying different things.

We were all so worried about Mum so Catherine and I went to hospital. We talked to the Staff Nurse, who said Mum was in good order and did not have a fracture, but that she had had an upset tummy again, and they couldn't discharge her until she had been free of this for at least 48 hours. We asked to see her, and were told we couldn't because of the norovirus. We really were as insistent as we felt we could be - even saying that we would be happy to wear protective clothing, but still we were refused. I know hospitals must take infection control seriously, but when it is your mother sick on a ward that you are worried about it is very difficult. If we had felt reassured about the quality of care she was receiving then we would have been more able to accept these rules, but it is a very different matter when you are worried that your relative is not being looked after properly. Knowing she was a matter of metres away on the other side of a few doors but that we could not see her, hug her, reassure her and ourselves. It was heartbreaking.

We realised the staff were not going to allow us to see Mum, and understood why, and so we gave a nurse a bag of goodies for her, including a card which I had written in to reassure her, explaining what was happening. I also included some drinks as every time one of us had spoken to her, she said she was terribly thirsty and couldn't reach her drink. I was assured by the nurse that she would go into Mum and open the card and read it to her, and make sure she could reach her drink at all times.

Wednesday did not bring any good news. Mum still had an upset tummy and she still had no phone in the side room, so we still couldn't speak to her. On Thursday I spoke to the ward again to get an update. They said the tummy bug seemed to be receding and that mum was "bright as a button" - which I thought a rather odd turn of phrase. I tried to ring Mum on the phone that had finally been provided for her in the side room. I continually got no answer so in the end I called the nurse's station and asked for someone to go in and help Mum answer it. When I spoke to her she sounded dreadful, very dry mouthed, and weak. She was openly crying, saying that she was unbelievably thirsty, and that she wasn't being treated very well. She told me that at a meal time that day, she had been woken by two nurses getting hold of her arms and hauling her up the bed, without first waking her up from a deep sleep. She said she told them that while she had been asleep she had unfortunately wet the bed and they said that she'd have to wait as they were busy. She was expected to sit in a wet bed and eat her lunch - on her own, without any help. She said to me that she was too weak to eat anything and all she wanted was a drink, but she couldn't open the bottle, as "my hands don't work and I'm so sleepy but no-one will tell me what's the matter with me". By the end of the conversation I could tell that just talking to me had exhausted her. Mum never complained - she was the bravest person I have ever met - she really really must have been desperate to have been telling me these things.

Not surprisingly, I was very upset after that phone call and so I rang the Sister back. She said that her nurses would never treat a patient in the way Mum has described, but that she would go in and see Mum and make sure she had a drink and was comfortable. She also assured me that she would explain to Mum what was happening.

On Friday I rang the ward. Again I was told Mum was much better, and in good spirits. That day Mum was moved back to the main ward. I still can't understand why this happened, as we had been repeatedly told that she needed to be free from diarrhoea for at least 48 hours (some told us 72

hours) before she could be moved. From the medical notes it is clear that mum still had diarrhoea when they moved her. When you haven't been allowed to see your own mother because the staff are apparently so concerned about infection control, and then they do things completely contrary to the rules, it can be hugely frustrating and difficult to understand.

Catherine went to the hospital on Friday and was allowed onto the "closed" ward. She was shocked at how Mum had deteriorated. She was very lethargic and seemed confused. She was very dry in her mouth and extremely thirsty. Mum loved ginger beer, so Catherine poured her some and she drank two glasses through a straw, with help. While she was there the on duty doctor did a ward round. He did not introduce himself, spoke quickly from the end of the bed and made no attempt to check that he was being understood. He said that she would not be discharged until at least Tuesday as he was worried about her upset tummy, and wanted the gastric team to look at her. Catherine asked whether Mum could be put on a saline drip as she was concerned that Mum was very dehydrated. He said that they would not do that as it was invasive and she was perfectly capable of drinking herself. We knew this was not the case. She needed help, and she wasn't getting it.

Catherine was also appalled that the basic personal hygiene that one would expect from nursing staff had not been carried out. She said Mum told her that she had not cleaned her teeth all week, in fact she couldn't as she had no money to buy toothpaste and the nurses had said they couldn't help. We would've brought some toothpaste in but no-one told us Mum needed some.

On Saturday I spoke to the ward staff at lunchtime and was told that if it wasn't a Saturday they would have discharged Mum as she was so much better. I was so pleased to hear this and glad that she must have made good progress since the day before.

I didn't realise that my sister Sally had been in to see Mum that morning and had had a chat with the on duty staff nurse who did not tell Sally that Mum could be discharged. Sally was in tears following her visit - she was utterly shocked at the state she found Mum to be in. She said that Mum was incredibly thin compared to how she had been one week before although her tummy seemed swollen, her chin was resting on her chest and her hands were curled into the shape of claws. She could only move her hands very slowly and had no control or movement in her arms. She could not grip anything. Sally said that Mum was too weak to say very much and she didn't recognise her own daughter, that she was so thirsty she drank nearly a whole can of ginger beer in one go – she didn't even attempt to hold the cup or move her head towards the straw. On the bedside table was a cold cup of Costa Coffee which Catherine had brought in the previous day, a cold cup of tea and a glass of flat Lucozade, which Catherine also brought. Sally said that there were a number of the little white paper pill cups that the nurses dispense pills in on Mum's bedside table - all with pills in them. One was dispersible paracetamol but there was no jug or glass of water for her to take it with. Sally asked the nurse what the pills were and she said "Oh dear , has she not taken them again?"and laughed. Sally said not only could Mum not take a pill on her own, she couldn't pick up her hand or move at all. How many times had this happened when we were not allowed in? Sally couldn't believe it when I told her that the Sister had said they would be happy to discharge her and Mum could go back to the nursing home - in fact had it not been a Saturday, they would have done this without us being involved, but they had no transport available at the weekend. Sally was amazed and we decided I should check that they were talking about the right patient. I double checked with

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hospital staff that they had this right, and was assured that they were happy to discharge her. We checked with the nursing home that they were happy for Mum to come home (we were not aware of her continued diarrhoea and nor were the nursing home staff) and then Sally organised a private ambulance to collect Mum and take her home. They arrived at approximately 8pm. We knew mum wasn't well but we felt that at least she would get proper care at the nursing home.

When Sally went to the hospital earlier in the day, she found the bag of goodies Catherine and I had taken in on Wednesday, which included the card explaining to Mum what was going on, unopened. The nurse had not given the card to Mum and read it to her as she promised me she would. It breaks my heart that Mum never got the chance to read it before she died. I find it very hard to understand how a "nurse" can be so uncaring.

The nurses at the nursing home were appalled by Mum's condition on arrival. In fact her GP was keen for Mum to be returned to hospital. By the time my sister Sally, who was there, had contacted us, the nurses told her that Mum was imminently going to die, and we decided that she should stay where she was. At this point Mum was drinking from a small sponge, unable to speak, and Sally had to run her finger around the inside of Mum's mouth to separate her teeth from her gums.

She died at 3.35 am.

During this very difficult week, I was liaising directly with the nurses at the home and was and am very grateful to them for their advice and support. The on-call GP who certified her death referred the case to the Coroner's office. A post mortem examination was carried out, which concluded death by natural causes. We were advised by her GPs that her death was not expected, and that they had been successfully treating the conditions picked up in the PM. We feel strongly that Mum was neglected in hospital and one way or another this led to her death. Mum's GP told me that an infirm lady who had difficulty mobilising was sent to hospital with a bruised hip, suspected fractured. A moribund terminal patient was sent home one week later. After discussing the situation at length with the Coroner's office, the Coroner decided he had enough evidence to open an adjournment. This is due to happen during the latter part of this year, or early 2011.

Since this ghastly week in January, I have worked very hard trying to get some sort of explanation from West Suffolk Hospital. All our family agreed that we did not want to take legal action, that what we wanted was to prevent this happening to anyone else, in any way that we could. I requested the medical notes, and found a number of issues and inaccuracies that cause great concern. We noticed that there wasn't a fluid balance chart in the notes and asked for this. At first we were told that it wasn't a "legal document" so wasn't "filed in medical notes". When we questioned this, they then said it was just because they hadn't kept one because they didn't need to.

We had a meeting with West Suffolk Hospital in March 2010. Unfortunately they were unable to satisfactorily answer our questions. In fact, we found their manner patronising at the very least. They insist that Mum was "fit for discharge". They do not accept that she deteriorated at all during her one week stay in hospital - even though we were telling them whilst she was there, and even though she died only a matter of hours after arriving home.

The minutes taken during our meeting were in parts an incorrect account of what was said. One example of this was that I had asked the Matron if I would be allowed to go around the wards and

see for myself that her promises that the standard of care was excellent were correct, and she agreed, stating she would be proud to do that. In the meeting minutes we received it said that it was agreed that I couldn't visit the wards for patient confidentiality reasons. A completely inaccurate representation of what was said.

We have another meeting arranged with the new Chief Executive of West Suffolk Hospital and with Mum's consultant. The points we have put to them, and are looking to have answered are as follows:- My family and her Doctor all feel strongly that the issue of Mum's rapid deterioration in the care of West Suffolk Hospital has not been properly addressed. She was admitted on 16th January as an elderly lady with a bruised hip. She was discharged a moribund, terminal patient. In the care of health professionals our mother deteriorated unnoticed. On the day she died, when she could not recognise her own daughter, or lift her head from the pillow, she was deemed fit for discharge by staff at West Suffolk Hospital.

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3. Elsie Poague

By her niece Susan Mistry

My aunt Mrs Elsie Poague, aged 99 years, was admitted to St Helier's Hospital in Carshalton, Surrey on the night of the 21st July 2009. My Aunt is very deaf and registered blind. She was basically fit and healthy, living at home on her own, which was her choice. She was very alert and capable of making her own decisions, she just needed help to run her life because of mobility and sensory problems. She had had a fall in her bedroom during the day which had resulted in an injury to her hip.

She was treated in A&E for a painful right upper leg and diagnosed with a fractured femur at 10.30pm. While in A&E she was washed, had an ECG, blood tests and a urine sample was taken. I gave details of her current medication and past history. The duty doctor told me that the Orthopaedic team would have to see her and would probably need information from me. It seemed very hard to get a drink anywhere in the hospital - the canteen was closed and drinks machines weren't working or were empty. There were no facilities in A&E.

She was admitted to the Clinical Admissions Unit at 11.30pm. The staff nurse on duty, after making my aunt comfortable and ensuring she was sleeping, took my contact details as she said that the orthopaedic team would need to speak to me for further information. She explained this might be in a few hours or in the morning.

A doctor from the consultant orthopaedic surgeons team phoned me at 1.53am on the 22nd July. She didn't want any information from me and had yet to see my Aunt. She told me that she was going to wake her up to examine her chest to see if there was any reason why she'd fallen and

broken her hip. When I suggested this was frightening and possibly confusing for a 99 year old lady who had been given morphine, had been through quite a lot in the previous 12 hours and had already been examined in A&E, she told me she had to be examined within 12 hours of being admitted. It seems to me that surely the time to have done this would have been before she was settled and had gone to sleep.

I phoned the unit the next day as requested at 10am to be told that they were still waiting for the doctors' rounds so they couldn't tell me what was happening and they would let me know. I wondered what the point of the doctor waking my aunt at 2am had been if they still couldn't tell me what was happening.

No-one attempted to get in touch with me before I visited late afternoon. I was told she would be having an operation the next day (the 23rd July), that the doctors had talked to her and she had signed a consent form.

I immediately felt concerned about how she had ended up signing a consent form. She would not have been able to read it and it was always a struggle to communicate with her because of her deafness. When I went to see her she was unaware of where she was and who was in the room with her.

I pointed out to the nurse that my Aunt lived on her own, the nurse said they had a full social history. The nurse found out the name of the doctor I had spoken to and the name of the surgeon in charge of her care and phoned me back – they didn't actually have that information in the notes.

My Aunt was transferred to another ward that evening. The operation was cancelled on July 23 and rescheduled for the next day. When I visited her after the operation to pin her hip, she was back in the ward and was unaware that the operation had taken place. She thought she had just been taken out of the ward and brought back, possibly to another ward.

On both the wards she was on I was struck by the lack of compassion and care in the nursing. This was not just the occasional nurse, in fact the odd caring nurse proved to be the exception. She was inevitably immobile, but on a number of occasions was left without the means of summoning help for hours on end. I gave her the bell push on 6 occasions after it had been put back on the wall out of her reach, presumably after she had been moved either into or out of bed. She was frequently left with her bedside table out of her reach and therefore no drink.

I felt it looked as though the nursing staff had come round, moved her as needed and left without giving a thought to what she might need after they had left; just lack of thought, interest or common humanity. I'm not suggesting it was malevolent. They often expressed amazement that she was as bright as she was for 99, but that didn't stop them leaving her lying flat in the bed (unnecessarily), without water and without means of summoning help.

After 4 weeks she was transferred to a care facility for rehabilitation, again under the auspices of the NHS, but there the situation was totally different. The staff were caring and thoughtful. Someone at last attended to her fingernails, which were long and filthy during her stay in hospital, and she looked better cared for than she had been for months.

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She was somewhat neglected when she went into hospital, from her own lifestyle choices. I asked if staff in the hospital could help with this, but it was always going to be something that the next shift would deal with and never happened. I visited at least every other day, but seldom saw the same nurse twice. There was no continuity of care. I'm sure they would have claimed to be very busy and understaffed. That didn't appear to be the case, there was never any sense of urgency and a lot of sitting around.

I did try to raise some issues over her general care and prognosis through the PALS system, where they were going to organise a meeting that I could attend. However that never happened, all I did get was a phone call from the sister in charge of the ward who told me that doctors and physios were too busy for a meeting, but did finally discuss my Aunt's future with me.

I feel that I am capable of fighting my corner with healthcare problems having worked in the NHS many years ago, and having been married to a GP, but often feel it is very hard for those who are not so strong.

4. Brigid Wainwright

I was admitted to Derriford Hospital in October last year through A&E Department as I was suffering very badly with breathing problems. I was 62 when I was admitted to hospital. For some people that might make me an "elderly" patient, but I don't consider that to be the case as I am normally fit and active. However what I saw happening to patients who really were suffering from the effects of old age really worried me and made me think about what would happen if I was admitted ten, twenty years from now.

I was admitted to an assessment ward and had excellent treatment there. I can't thank enough the staff nurse for taking me through a crisis. I am also grateful to the other staff who were there as needed in a very busy ward with lots going on.

The staff nurse kindly came to see me before she went off shift, to say that I would probably be transferred to another ward, so I probably would not see her again. A very nice and important touch.

Before I was transferred, there was not time for me to have a nebuliser, so the nurse asked me to tell the staff in the new ward that I was due for one. I was wheeled to a bed in the new ward, there was a nurse there looking at paperwork who then walked out. I didn't see any nursing staff on the ward for another 3 hours.

All patients should be greeted, assessed, asked what their needs are, from them or their family (if they are too ill). Those needs should be recorded in the notes. They should be shown where the washing/toilet facilities are, and told if they should use them or ask for a bed pan . The name that they are <u>known</u> by should be put on the board behind them. They should be shown the call button and how to use it. The call button should be responded to promptly.

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It has to be remembered that people are very ill when they are admitted to hospital and are not going to be as lucid as they might be in normal life.

I had acute bronchitis and pains in my back. I was left by the bed, not knowing whether I should get in. I could not recognise the call button as it was different to the one in the other ward. I needed the toilet, but did not know whether I was allowed to walk to one. When I did, they all seemed to be male ones. I was not aware of the sign system for which were male and which female.

I got my nebuliser treatment 3 hours late.

I needed tissues as I was bringing up phlegm but my husband had to bring some in. I asked for something to put the dirty ones in and there was not even paper bags attached to the bed table as there had been in other wards, I did not get anything. I made do with an old tissue box, this was never taken away and replaced.

I asked for something to be sick in, but was given nothing. I was sick on the hospital gown that had been given to me. Luckily, I had my own nightwear by then. The dirty gown was never taken away in the week I was there.

I asked for another pillow because I could only sleep upright and needed extra support in my lower back, so that the painful part of my back did not touch anything. I got one after 3 days.

As I was having breathing difficulties, the doctor said I should have the nebuliser on demand during the night. The staff nurse told me to press the buzzer when I needed it and she would come. I woke up coughing and gasping and pressed the buzzer. It was a 6 bed ward and I was by the window. The staff nurse and auxiliary nurse were in the ward at the other end, changing a mattress for someone who was due to go home the following day. The auxiliary nurse came over, went round the bed, switched the buzzer off and walked away. It would have been clear to her that I was in distress. She went back to the mattress changing and I thought she would have told the staff nurse that I needed help. Nobody came and both of them walked out the ward. I just sat on the bed crying, not knowing what to do. It must have been about an hour later, the staff nurse came back, walked up to my bed, and said that I should have pressed the buzzer if I needed her. I told her what had happened, she did not comment, just gave me the treatment. She responded promptly after that.

This was my experience, but I also worried deeply about the care other patients on the ward were getting, particularly the elderly.

One elderly lady next to me was very frail and could not support herself or sit up unaided. She also seemed confused, bewildered, frightened and unable to ask for anything very easily. She would flop in the bed against the guard rails and nobody would help her. I had to get out of bed and make her as comfortable as I could with some blankets to support and protect her. She clearly thought she was back on the farm with her arm trapped in a gate with the cows threatening her. She was calling for her husband to help her. Nobody came. The nurses did not answer buttons pressed by other patients.

It wasn't until the day I was going home that I discovered from her daughter, that the lady was not known by her first given name , but by her second name. Her first name was the same as her mother's. She must have been even more confused when everyone seemed to be calling to her mother. Her daughter had left special drinks and snacks in her cupboard and left specific instructions. They had been forgotten and ignored.

Food was brought to her, left to go cold on the bed table which she could not reach. She needed help to eat and drink.

Over a couple of days and nights she kept asking to go home, it was quite distressing, not only to her, but other patients when she was ignored. I spent a lot of time trying to help her and I was very ill myself

Another elderly lady was treated well the first day, but once she was stabilized, not given much understanding. She was left for a long time when she had soiled herself. Everyone was aware, because of the smell. How uncomfortable and embarrassing it was for her.

One time, her spectacles were left out of reach so she could not see to eat. I had to get out of bed and retrieve them for her.

Another patient pressed the buzzer because she needed a 'bag' changed. Nobody came. She was in such distress having had to wait so long, I went in search of the appropriate nurse. I found her in another section and told her of the urgent need. She said she would come, but she did not. I believe the lady's bag burst.

One patient would regularly have 4 or more visitors. One day there were 12 I think, including children. They took all the available chairs, a lot of space, were noisy and other people's visitors had to stand, including one who was clearly disabled. I thought visitors were supposed to be limited in number because of the risk of infections?

That particular patient had a crisis as she was coming round after an operation. The nurse pressed the button for the crash team, but an oxygen mask had not been available by the bed so the nurse had to hunt the ward for a free unused one. Luckily the next bed was empty and there was one there, but it wasted valuable seconds, luckily it didn't seem there were any ill effects from the delay.

When asked by patients why the nurses did not respond to the call button, they were told that they were all very busy and worked off their feet. Yet when I went to the bathroom or to the desk, I could see no evidence of a lot of activity in other bays, but a lot of voices from the staff rooms. When asked about this, I was told it was briefings for handover.

Other patients should not have to do a nurse's job.

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5. Francesco Barsciglie

By his wife Margaret Clarke

My husband had end stage kidney disease which meant he had contact with hospitals for many years. He was initially on dialysis, had a transplant and then when this failed went back on dialysis. We had had contact with the Royal Devon and Exeter (RD&E) hospital for over 20 years and when he first attended there he had what can only be described as 5* treatment with fantastic care at all times. His life was saved several times.

When he went back on dialysis he was initially at a small unit and then transferred about three years ago to the RD&E. Over the last 10 years I think there has been a steady decline in services. The care my husband received in the week of his death can't really be described as care. I would say that our dog, our cat and even our car have all received better treatment than he did in the days before he died. Our cat had a stroke on a Sunday morning. The vet came out and we discussed what was going to be done and treatment was given. When the car went in for its last MOT it was checked in politely and it was later explained what needed doing. Our dog had had a chronic illness which needed regular treatment. All at the vet's surgery were kindness itself.

Since obtaining Foundation status I would say that the hospital is more concerned with interior décor and image than in patient treatment. It has recently spent over £1 million on refurbishment of the entrance. Maybe they should have spent it on more nurses instead. I spoke to a number of patients and staff when my husband was getting his dialysis. Many thought it was a ridiculous waste of money.

Before describing what happened to my husband I would like to highlight how I had already learnt the Trust was not interested in listening to patients. On the first day that he attended for dialysis I went to wait in the waiting room off the unit. There were three elderly patients waiting there. I do not feel the cold but that waiting room was freezing – it was a very cold winter's day but you didn't expect that degree of cold in a hospital. The waiting room was more or less open to the outside. When I mentioned how cold it was they said 'Oh, it's always like this'. The next time I had to wait there I found an old lady who had been waiting for three hours unable to move in that cold. When I

put in a complaint I was told that 'No-one else has complained'. I later found that there were complaints going back 8 years.

A few weeks ago two celebrities, also kidney patients, were talking on BBC Breakfast about their experiences on dialysis and they said that one of their problems was always feeling cold. They were lucky that, unlike the patients at Exeter, they didn't have to wait for hours in that waiting room. It was only after a huge correspondence, which the Trust quite obviously found a nuisance, and after the intervention of a patients' complaints body that something was finally done. During the 9 years that patients had been using that waiting room in those conditions the Trust built a large comfortably-furnished well-heated administration block only yards away from where 80+ year olds were sitting in the freezing cold.

On Friday 9th January 2010 my husband went to the hospital for dialysis but was in too much pain to go on the machine. He had a lot of pain in his shoulder and he couldn't have lain still for 4 hours. A doctor from the pain clinic tried to inject some medication into his shoulder but it was too swollen with fluid. Now that I have seen the post mortem report and the hospital response to my complaint, it seems he was actually bleeding into his shoulder joint. He said he would attend the next day for dialysis, hoping it would have improved.

During that evening the pain became unbearable and started in his stomach as well. I called the out of hours GP service. The doctor who came rang the hospital and had a long argument with a consultant on call. He later wrote in his report that he considered the reply that he got was 'inappropriate' as she would not give him any advice. When he closed off the call he said that he had never had a conversation like that with a fellow doctor. She had refused to accept him for admission to the hospital even though that was where he was being treated regularly and where he was due on dialysis the next day. She was insisting that he be sent to another hospital in the other direction without any facilities for renal patients. This was on one of the worst nights of the year with the whole county almost at a standstill with ice and snow. I managed to get the phone number of my husband's consultant and the doctor spoke to her. She agreed with him that he should go to the RD&E. Unfortunately instead of being admitted as was intended he was taken to A&E.

We arrived at A&E after a hazardous ambulance trip at about 10 o'clock. We felt we were a nuisance. Any enquiry as to when he might get some pain relief or see anyone was met with 'We're busy' or 'We've got a head injury'. It was clearly implied that we shouldn't be there. It did not seem to me that they were all that busy. At one stage a nurse came and told my husband he was offering her 'resistance'. We had no idea what she meant and took it to be some sort of psychobabble. No one from the renal department came to see him. At 4 o'clock we were told we were going home. We were quite simply gobsmacked as the whole county was snowed under and he was due on dialysis only hours later. I had taken a trolley with me as it never entered my head that he would be coming home. We didn't feel we could say anything at the time. My husband felt exhausted and that he wasn't really getting treatment anyway, so we just went along with it. You just don't feel you can challenge them. We assumed we would go home in an ambulance but were told we had to get a taxi. We had an hour's journey home without meeting another car and the driver was concerned that he wouldn't get back to Exeter safely.

Fortunately by midday there had been some thawing and I took him back for dialysis. This was cut short because of the pain and we came home. He was feeling really unwell by now and that evening vomited a large bowlful of dark liquid. There was little food in it as he had hardly eaten for several days. He managed to sleep a little but in the morning was still the same. He vomited two large bowlfuls of liquid. I called the out of hours doctor and he said that, if the feeling of sickness continued, to go and pick up some anti-sickness medication at Okehampton hospital. I later rang to say I would do this as he still felt sick. It took me about 1½ hours to go to Okehampton and back. This was on the Sunday and I was later to remember how the vet had reacted when I had phoned him about our cat on a Sunday morning. At that time we were living near Exmoor and I knew how the vets were prepared to go out in all weather to tend animals. Unfortunately my husband wasn't born a cat.

He spent the whole of Sunday in pain and lying down. We managed to get to the RD&E the next day and I think it should have been clear to anyone at that stage that he was very ill. Another patient commented how 'terrible' he looked. He had written out a list of all his symptoms just before he left for the hospital and even his writing shows what a state he is in, but he was desperate to get someone to listen to him. He had not been to the toilet for several days, had not eaten and had vomited about 8 pints over the weekend. He had spasms and was in huge pain. An effort was made to dialyse him. A doctor came to see him and said he should have a chest and abdomen X-ray before going onto the ward. After everything that he'd already been through and now knowing what was to come, I feel strongly that he should have been seen as an emergency then.

When he was taken off the machine we went to a nearby room to wait to go for X-ray. I kept going back to ask when we could go but there was no sense of urgency at all. The last time I asked I was told that they would probably have to get someone in specially to X-ray him. As we were in a large general hospital with someone in X-ray all evening this was quite clearly daft and I then took the X-ray form from the desk and wheeled him over to X-ray where he was dealt with quickly. He was doubled up in pain but was still talking normally and alert. I then wheeled him to the ward.

When we got to the ward someone called out to ask his name and when I answered just pointed to a bed. By this time he was trying to lie down and then trying sitting and then lying down again he was in such pain. Whenever I tried to get anyone's attention it was always met with 'We're busy'. Almost the last thing he said to me was 'Why are you afraid of them?' but I didn't want to be a nuisance. I now bitterly regret not having made a fuss. We had arrived on the ward at about 6. A doctor finally saw him at about 9 and gave him pain relief. I had been told that I couldn't stay so I left the ward at about 10. I thought he would get some sleep and I would go back the next morning early to begin the battle. I was rung early that morning to be told that he had died. When I left the ward I had rung a friend to tell her I was exhausted – not physically but from having to deal with the hospital and to get anyone to do anything. The guilt I feel at having left the ward that night is unimaginable. It is my first thought every day. I did not even say goodbye as I knew he would be begging me to ask them again if I could stay and I couldn't face dealing with them any more that night. I can now only remember a time years before when he had been ill and the hospital could not have been faulted. Attention was given almost before it was needed. Bells were answered quickly and one never felt a nuisance. The difference was unbelievable.

I received a phone call the following morning to say he had died. When I arrived at the hospital a few hours after his death I asked if I could speak to someone who was with him when he died. Initially I was told I could but that the nurse concerned had gone off duty and would be sleeping. I said I would come in at any time when it would be possible to speak to her. The next day I was told that the nurse had gone on holiday. I said I would like to speak to her on her return. It seemed to me like a series of excuses.

I was contacted later to be told that the matron did not consider it 'appropriate' for me to talk to the nurse but would I like to come to a meeting with a doctor and the matron (neither of whom had been present and who would be merely reading from the notes made). Initially I agreed but then rang to say I couldn't see the point in this and would prefer to have a report in writing as to what had happened. The matron said she would have to check if this were possible 'legally'.

I had left my husband alert and talking that night but in great pain and looking very ill. He died only hours later. I was also concerned at his having been sent home from A&E only days before and the lack of treatment over the weekend. I contacted ICAS who helped me write a complaints letter, some of which I have used to write this story.

When I received the hospital's reply I was shocked at quite a lot of things in it. The letter said that he should never have gone to A&E but should have been admitted through medical admissions. We should never had had that night in A&E with no-one paying any attention and being sent home at 4 in the morning. It claimed that he had wanted to go home but I sat in A&E for 6 hours that night with a night bag next to me waiting for us to be moved on. If anything was said it might have been along the lines of 'We might as well be at home'.

It also seems that when he was reviewed first on the dialysis unit they thought the abdominal pain was from his constipation and that it wasn't related to the pain he had in his shoulder.

The reply letter describes the treatment he was given, repeatedly listing his observations, heart rate, blood pressure, blood oxygen with no explanation. The notes apparently record a trainee doctor reviewing him and listing his problems as severe abdominal pain and vomiting. It is written that he had something called 'guarding' which was a sign that there might be something very wrong with his abdomen but again this was not explained to me the first time the term was used.

The explanation of his treatment then gets very complicated. I have asked a friend with medical training to review it and try to explain it to me. One of the blood tests taken indicates that his blood clotting was very badly reduced (the figures are INR 9.9 and prothrombin time 119). The post mortem has shown he was bleeding into his stomach. The vomiting and the pain was because of this and this is almost certainly why he died.

My friend has explained that you can never be certain, when reviewing the care for someone who was as unwell as my husband was, if it was correct or not. It seems he was visited by different doctors during the night. It seems that despite the early recognition that he might be bleeding internally by the medical doctors the surgical doctors didn't think that was the problem. The medical team gave him a treatment to try and correct his clotting but they don't seem to have checked it again in the almost 8 hours they were looking after him. The treatment is also recorded

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as being given at 23.30. It seems this was at least a couple of hours after they had realised there was a problem. His haemoglobin was lower than usual when they first admitted him and had fallen again when checked. This is another sign he was bleeding. But there is no record of them checking it again to see whether it was getting worse or improving.

The poor record keeping means that their explanation of events says things like "The on-call medical SHO reviewed Mr Barsciglie between 22.00 on 11 January 2010 and 01.00 on 12 January 2010". Common sense tells you that a three hour window for a very unwell man is really not accurate enough. The letter also says he was reviewed again by the doctor but that 'no time was recorded'. So, for the last time that he was seen by a doctor, when the observations still weren't right, they can't tell me a time that it happened. It says they were going to repeat his blood tests in the morning. They never got the chance.

The nursing observations were last recorded at 05.55. They still weren't right with his blood pressure low and heart going fast. In fact they had got worse after initially getting better with the first lot of fluids they had given him. A nurse came back for what they've described as a 'routine check' about half an hour after taking those observations. He was 'unresponsive' and after twenty minutes of trying to revive him he was pronounced dead.

And throughout all this, with doctors visiting him in the night, giving him treatment, nobody called me to say come in, he's not well. I woke up at 05.00 and I was tempted to ring the hospital but the way I had felt on the ward I just thought they would think I was a nuisance.

My husband wrote the note detailing his symptoms 18 hours before he died. After being sent out of A&E at 4 in the morning and after a weekend of pain and vomiting he was desperate for someone to really help. I think anyone reading that and reading of the 'care' he received will doubt if it was sufficient and will understand why I will never forgive myself for leaving the ward that night. I waited on the ward for 4 hours. I should have known that he was unlikely to get sufficient care.

The hospital have apologised for some of the things that went wrong. They have said lessons are learned. Who is to check this? I don't believe them.

6. David Perkins

By his wife Maureen Perkins

Firstly I would like to praise and thank the many wonderful nursing staff, physiotherapists and doctors that have helped with the care of my husband David J Perkins. However, sadly there have been some occasions where we have experienced some of the worse care imaginable. All of us using the NHS know how wonderful it can be, but I have now learned how very terribly it can let people down. When this happens we must speak out. I work in a residential home for children with severe emotional and behavioural problems and have always prided myself on ensuring I treated them with the upmost respect and gave them the very best care I could. I thought this was how all people working in caring professions acted, but during David's time in hospital I have learned that is sadly not the case.

David came into Southend Hospital on the 5th July 2009 fairly well, albeit to have a major operation to remove his bladder and prostate after having a tumour removed at Basildon hospital some months earlier, no problems there. He had previously been at Southend Hospital in February and March for chemotherapy where the staff had been extremely kind and courteous. He was told the best way to be sure the cancer did not return was to have the bladder removed.

Sadly, he was taken into critical care on the 11th July 2009 after inhaling his own vomit which in turn caused an infection that attacked vital organs and left him in a poor state of health and almost paralysed. I had been worried about David the night before because he seemed to be hallucinating and he was confused. I had told the nursing staff but they just told me not to worry that "it was just

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the drugs". I stayed until the very end of visiting time because I felt he wasn't right but no one seemed concerned.

On the 29th September he was moved to HDU and this is where the first problems really started. On 10th October David seemed very confused and did not recognise his grandson. He was calling out to other patients' relatives as he seemed to think he was back in the army. We found this very distressing and although the nurses had tried to explain all his observations were ok he had a slight temperature and we wanted to see a Doctor. We were told there was only one on duty and she would not really be able to help as she was not my husband's Doctor. We had to complain to get them to bleep a doctor to come and two hours later we were still waiting for them to arrive. I had to wait for over three weeks to see David's Consultant after he was admitted to the HDU.

I would often find him soiled. They would always say that he must've just done it. I remember one time on the 17th October he had pyjama bottoms put on him which were so tight they had badly marked his stomach and had also ruptured his surgical bag allowing him to be covered in urine and left in faeces, which had been covered up with tissue. The nurse looking after him said pyjamas had to be put on him for his own dignity. But no apology was given for the state he had been left in. David was always a very proud man, he always kept himself immaculate. I was horrified to see his dignity taken away like that.

On the 18th October I found him calling for help and almost falling out of the chair he had been put in, thus having to use my own body to support him until the physiotherapist, some 25 minutes later, responded.

On the 8th November there was an incident where a physiotherapist had somehow managed to allow David to fall back whilst he was in a wheelchair. I was told David was unhurt although he said he banged his head and back. The Physiotherapist rushed off, without checking to see if David was ok, because she said he had to report the incident because she had a bruise and she had almost choked him. I asked what she meant, and she said whilst swabbing his mouth he had begun to choke. Both myself and my daughter were trained by the staff to swab his mouth and never caused him to choke.

There were lots of other incidents, that perhaps don't seem as important but really wear you down and make you lose trust. David was offered jelly for lunch which was clearly written on the board items that were not allowed, which I had to point out. Sometimes they would shave him and I would see they had cut him. We would ask how that had happened and no one seemed to care. In the end my daughter told them she would do it and she brought in an electric shaver and did it herself. The staff wouldn't always wear gloves, one time I remember a doctor came to put a drip in, and I asked him to wear gloves and he refused. I spoke to the nurse and she persuaded him to wear one glove.

David needed to be lifted with a hoist in and out of his bed into the chair. Twice he fell onto the floor because they had put the hoist on incorrectly. They said he needed extra pillows to ensure he should prop himself up in bed. We were told they didn't have any extra pillows, we had to go and buy pillows. We went and bought 4 or 5 pillows.

I had started to highlight regularly to the staff these problems and I think they labelled me as a moaner, they thought I was just negative. This is my husband, who I have loved and cared for my

entire adult life. I wanted the very best for him, and certainly not the kinds of problems I saw. In one meeting a manager who I grew to dislike intensely, said "If you keep making these complaints the nurses won't want to look after him and I won't want him on my ward." I replied "excuse me, this is not your ward, this is for the patients". Then he walked off. Another time he made a strange mark, I can't remember his exact words, something like "If that was me, I would've put a pillow over your face". The other staff present seemed shocked he had said it and he later apologized, but obviously I felt our relationship had broken down. Yet I still had to trust him to look after my husband.

On one occasion a specialist nurse came to discuss cancer care with David's team. I asked to speak to her but she said she didn't have time. I arranged a time to come and see her but when I did she said she was still busy and told me to wait. Then she said she couldn't discuss his care with me because it was confidential medical information. I said I would be looking after him if he came home and I needed to know what was happening but she still wouldn't discuss what was happening.

He was moved to a general ward at 3am one night, he must've been disorientated and unsure of what was happening. When I asked why he had been moved in the middle of the night, I was told they needed the bed. I pointed out that there was another bed, but they said they didn't have the funding for the staff to use it. I am still waiting for a reason why this was done, so far the explanation given is unsatisfactory. The consultant explaining this to me was very kind and sympathetic, and could not say that was what he would've done. Fortunately the outreach team that looked after him were marvellous. They spent time with him, held his hand, spoke to him. I felt they genuinely cared. The surgical sister was also brilliant.

But eventually they felt David needed one on one care again and this was agreed with the sister on the ward who was also brilliant. After what had happened I said I didn't want to leave. They assigned agency nurses to look after him, and many seemed disinterested. They would sometimes sit in the chair in his room fast asleep. They were being paid to look after David. After approximately 5 days on this general ward he was beginning to make progress again. Then he was moved to another ward and the nightmare began all over again.

Two days before he died I went in to see him covered in vomit. It was dried so it must've been there for some time. It was all down his clothes and around his mouth. I really was at wits end by then. I went back to the nurses and said how "dare you leave him like this" and they said we have 28 other patients. I told them to go away, I would do it.

That evening I couldn't sleep, I felt very restless. I phoned the ward to see how he was doing and suggested I might come back in. They assured me everything was fine, that I didn't need to come in. I was called at 7am the next morning and told to come in as he had taken a turn for the worse. When I arrived he was being put in a lift to take him to critical care. I smiled at him and said "hello darling", he opened his eyes and smiled at me. I never communicated with him again. I went with him and I was asked to wait and settle him. I asked them who was on duty last night, they said they didn't know.

After he had been moved and settled I went to the canteen to try and clear my mind. I saw a lady who was near him on the ward. She asked me how he was and said "I could hear him, he was very

distressed at 3.00am". Her mother was there and said to me "you know my love, you can't trust them on there." I said, sadly, that was what I now believed.

I went back to see him and other family arrived. We were told there wasn't really any hope. The nurse looking after him was wonderful. They asked us to give them a moment to care for him. We came back later and the nurse said "I am sorry my love, he has passed away." This nurse, who had looked after David when he first went on to critical care, was outstanding. The whole team were. They trimmed his hair, they shaved him without cutting him, they even trimmed the hair in his nose and ears. They were exceptional. This nurse was very kind and considerate and had always been. I cannot praise him enough. When he had arrived back on the ward he said to me "what has happened to him? His bottom was black and blue with bed sores. We explained we had been finding him lying in a soiled bed.

David worked his entire life, he was still working at 71 when he went into hospital. He had not been in hospital since he was 11 to have his tonsils out, but when he needed the NHS it, it failed him.

I wanted to bring him home, if he was going to die I wanted him to have his family around him as I no longer had trust in the hospitals. He trusted me, I trusted him. I regret not taking him out. Had it been the other way round he could've picked me up and taken me out but I couldn't. I had to leave him in their hands.

It has nothing to do with money. I don't want money, I can't be compensated for what happened to my husband. If you gave me a million pounds I would give it away. What I want is a change of practice. I don't want the same to happen again. It seems you have to fight the whole time to get anything like good care and then fight when you complain.

7. Jean Kellard

By her daughter Carole Brown

My mother tells people she has led a wonderful life and that she is very proud of her children. We care deeply for her. I would always want the very best for her. She has worked hard her entire life and still works now. My mum has worked hard and paid national insurance all her life.

Besides when she was having children my mother has only ever been in hospital once before in the 1980's for suspected kidney problems. She tells us that the care then was wonderful and she has really struggled to understand how things have changed with her experience in Leeds General Infirmary last year.

I don't know if some staff have forgotten one of the fundamental things about being ill is that yes you need the clinical treatment, but you also need the care and compassion.

I was in Harrogate District hospital in February this year and the care was completely different to the care I witnessed my mother receiving. They had the same shortage of staff, but there was never anybody congregating around desks, they were always trying to help, always made sure you had your call bell. I cannot tell you how different it was. I know people who will now not go to Leeds for treatment, they go to Harrogate instead, because they think the care isn't good enough.

It seems in some ways the NHS has gone backward despite all the extra money. They are requiring nurses to have degrees. Yes you need a nurse to be intelligent but you also need them to have caring qualities. You learn that from being on the job. I would worry that doing a degree might distance them from the job. But at the same time there weren't enough nurses. I got the impression that because they couldn't look after patients in the way they wanted to, they had learnt to switch off.

My mother was admitted to Medical Reception at the LGI in Leeds on 5th November 2010. We arrived at about 4.30pm and it took until 10.30 pm before she had had a chest x-ray. It took the 5th year medical students 7 attempts to insert a cannula for the drips for antibiotics and saline in her left arm. In the end the other medical student took over and put the needle in her right arm. Her left

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arm was a mass of bruising for weeks. Mum was put on oxygen, which she was subsequently on for about three days but I had to go looking for someone the next day to find out what was happening to her.

The following day when we arrived at 1.30pm we were told that mum would be moved to the St James Respiratory Unit that day and they were waiting for the transport. They moved her to some kind of waiting ward and while she was there they didn’t give her her antibiotics, or continue her drip or even carry out basic observations. The transport didn't come until 6.30pm. In order to find any information out at all I had to go and find someone because no information was offered.

We arrived at St James at 7pm and no-one rushed to see my mum besides a nurse taking some observations. At 8pm we left her trying to sleep as she was exhausted. The following day I rang in the morning to try and find out more information about her treatment but I was just told that my mum was stable and the consultant would see her later. My brother came over from Liverpool and went to see her at 2pm and asked about her treatment and went straight back to Liverpool so we didn't have any communication with him before I went to see her at 5.30pm.

When I got there my mother was not in her bed and when I went to find her I was told that she was in the toilet and that the nurse would get her. My mother said she had been there pressing the buzzer for some time and no-one had arrived to take her back to her bed until I arrived.

I asked about whether there was a treatment plan and was told that the nurse had informed my brother and asked why did I now want to know. The nurse was quite rude but when I managed to collar a doctor he just said that the consultant had seen her and that my mother would probably move to one of the other wards that evening. I still wasn't given any proper information and it seemed that when relatives arrived the staff did their best to disappear. The following day things were worse.

I arrived at 1.30pm and she was missing again. This time when I went to find her it turned out that she had been half an hour sitting in the toilet pulling a buzzer that didn't work and if I hadn't looked for her, god knows how long she would have been there. She complained of being really cold. When we got her back to bed she told me that she had started coughing in the night and pressed her buzzer but no-one arrived and unfortunately the coughing made her wet the bed. When someone finally arrived she was dumped on the commode very ungraciously and the nurse tutted and muttered all the time she had to change the bed. My mother said she felt really humiliated and upset and did not want to stay another night in the place and was adamant that she wanted me to take her home. Luckily, when I asked, the nurse told me that the consultant had said that mum could go home that evening. But if I hadn't asked I wonder just when we would have been told we could take her home.

I had rung that morning for information but was put off, they said they were really busy. All the ladies in the little ward complained to me that no-one took any notice of the buzzers and in fact every time I arrived her buzzer was not in reach. Not surprisingly my mother does not consider that she has had a good experience and neither do I. Other people have told me that the ward my mother was on was not good, that there was no care really. God help patients who had no visiting relatives. I could not believe that there wasn't even a microwave to heat some rice pudding up that I had taken in to tempt her as the food was inedible.

Another thing my mother noticed was that when they came and replaced the jugs of water on the patient tables, they never changed the cups. You were expected to keep drinking from the same cup day in day out without it being cleaned.

I sent a complaint to the Trust and it took over 5 months for them to send me their response. In that time they wrote to me 3 more times to apologise that it was going to take longer than expected to investigate the complaint. I really don't understand why it takes 5 months to investigate a relatively simple complaint like mine.

When I received the response I was really upset because the letter was just one paragraph after another of token apologies. I did not get the impression that my complaint had been taken seriously.

In fact my neighbour has been in the same ward several times since as he suffers respiratory problems and he says the treatment is still the same. He says his carer goes and finds the same problems happening. In fact the last time he was in he said he had a diabetic hypo because no-one would listen to him so in the end he discharged himself, enduring a lot of bullying behaviour, even from the matron, when they realised that was what he was doing. What is the point in apologising if you don't change practice as a result?

I have decided to take part in this report in the hope that others might be spared this undignified treatment; that something might be set in train to stop these awful standards from continuing. I am ashamed that this is England, supposedly a developed country doing things like hosting the Olympics and meetings of world leaders, but we give our own people this sort of treatment. Frankly it makes me scared for when I am my mother's age.

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8. Muriel Browning

By her daughter Angela Lawrence

My mother, Mrs Muriel Browning, aged 96, came into Ipswich Hospital for an X-ray on Friday July 30th 2009 after falling at Glebe House Retirement Home in Hollesley where she's been living since June. A small fracture of her left hip was discovered and she was admitted to a ward. She died on the 27th August, the day the Patients Association published its report into neglectful hospital care. I contacted the local media that day and even did an interview about what had been happening to my mother. I felt somehow vindicated when I learned from the Patients' Assn report that I wasn't alone with my anger at my mother's treatment – it was all too sadly widespread in our hospitals.

My mother spent her life as a teacher and by all accounts she was inspirational in the teaching of music throughout her teaching career. A bright, feisty and independent lady - so sad that she should have ended her days in such indignity.

During my first visit to see my mother on the afternoon she was admitted she was desperately trying to get out of bed to go to the toilet. She was swinging her legs over the side and I was afraid she'd propel herself off the slippery plastic mattress cover. I told a nurse she should have cot sides to the bed because I was afraid she would fall out.

The next morning she was operated on, the hip pinned. I rang the ward to see how she was. The staff nurse/sister told me she had fallen out of bed on Friday night and had been found on the floor by the night staff. I told her I'd told a nurse the previous afternoon that she'd most certainly fall out if cot sides weren't installed. 'We couldn't put them on until we'd done an assessment on her,' was her defensive reply. This was the first of a string of defensive excuses I received for negligent nursing practices I came across during the three weeks my mother was in hospital. Who knows how much worse her fracture became as a result of that fall from a high hospital bed? No-one has told me.

My mother then suffered a 'silent heart attack' so was moved to a cardiac ward. She then got a chest infection. A nurse, the most sympathetic I came across in the time I was there, handed me three leaflets on the care of the dying and said 'it will be a matter of days rather than weeks.' I was prepared for the worst, though totally shocked that it had come to this, and so rapidly.

Mum rallied, but had constipation (this was common in my mother) and was treated with three different drugs. She couldn't open her bowels on a bed-pan, but the nurses were very reluctant to get her onto a commode. She was repeatedly messing the bed and finding it distressing. As a result the physiotherapy she should have been getting, in order to get her back on her feet and back into her residential home, stopped. From the beginning of her hospitalisation I did not feel the physios were doing enough to encourage my mother back on her feet. I tried to encourage her on one occasion, lifting her into the support frame and saying, 'you're doing great, Mum.' She snapped back 'Oh shut up!' which was her normal reaction to being asked to do something. She had dementia and had lost all social graces at this stage. No, I wasn't bullying her, just being firm and positive, which I'd learnt over the past few years of caring for her was the only way to get my mother to do things.

Eventually she was transferred to another ward and the care was even more appalling.

I visited on 14th August and I was deeply upset at what I found. The single-person side room she was in reeked of excrement. I had to immediately climb on a chair and fling open the window it was so overpowering. She was lying in a soiled bed and a filthy, diarrhoea-filled incontinence pad. She had been scratching at her sore rear end and her fingers were filthy with excrement.
A nurse was giving out hot drinks. I asked if someone could change Mum's pad. 'You'll have to wait, I'm doing the drinks,' she replied. It appeared she was the only nurse on duty at the time in the ward. My mother was moaning in real distress; she wanted to go to the toilet. I asked the same nurse if she could put her on a commode. 'I can't do that,' she said. 'I'm on my own.' She came back half an hour later to change my mother's pad. So my mother would be forced to soil that one too, and probably spend the night in yet more discomfort. Why couldn't she be allowed to use a commode? I suspect it's just too much trouble for the staff.

I also asked her if she could scrub my mother's fingers and nails as they were clogged with excrement. I considered this unhygienic for touching food or her drinking cup. 'Haven't you got a

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pair of nail scissors in your bag so you can cut her nails yourself?' she demanded. 'No,' I replied. I was shocked. Surely it's the staff's job to look after patients, keeping them clean and hygienic, not relatives,

I was also left wondering whether anyone was feeding my mother, helping her to drink. She was unable to reach the cup on her bedside table so I doubted she could manage to cope with a plate of food. If I hadn't helped her that day drink her hot chocolate with a straw she would not have had a single drop of it. I asked at the nurses' station if I could have an air spray to kill the smell in the room. 'We don't have air sprays,' I was told.

She also needed help feeding and drinking but I was sure she wasn't getting that. The food was also dreadful. One day I decided to take a picture the meal they delivered to her tray which she was totally unable to eat; a large lump of boiled chicken and pasta. Impossible to cut up and totally indigestible! Even when I cut small pieces for her she found it too dry to eat. How can this be suitable invalid food for someone in her condition? Unbelievable.

On the 18th of August I visited mum again. She had continuous diarrhoea as a result of all the laxatives being given her. Because she wasn't being put on a commode she was repeatedly lying in diarrhoea and urine soaked incontinence pads. I kept arriving to find her fingers and nails covered in excrement. I repeatedly asked the nursing staff about this until in the end one said 'If I bring you a bowl of water you can scrub your mother's nails yourself.' I couldn't believe the dirt that came out from under them. When I was doing this mum asked me to take her socks off so I pulled back the bed sheets to do this. I was horrified to find mum had diarrhoea and they hadn't even put an incontinence pad on her.

She had been crying out in pain and distress and now I could see why. Her nether regions were covered in a very raw red rash which was now being aggravated by the incontinence. Surely you should be able to trust the essentials of personal hygiene to be looked after. What happens to patients who don't have someone who can come and wash their hands for them?

I was so angry at what I had found that I went straight to the nurses' station and asked to see her doctor. I demanded he come and see the state mum was in. When I showed him he said "This is a nursing issue". I replied "You're her doctor, why don't you tell them what to do?" He stated he couldn't do that. Instead he sorted out an impromptu meeting with him and sister. I explained I was unhappy with the care my mother was receiving. Asking that my mother be put on a commode, the nurse replied 'We don't have the staff to watch over a patient on a commode.' 'Why not strap her in, so she doesn't fall off? She'd be quite happy sitting there for an hour – she used to do that at home,' I told her. 'Rules and regulations; we're not allowed to use restraints,' was her answer. As to feeding, I said someone should persist in making her eat and drink. I explained that when I came in I had helped her drink through a straw, which she was happy to do. The nurse said defensively "Oh and do you think that's something **you** shouldn't have to do?" I replied of course not, but that I was worried no one else was helping her.

On Sunday August 23rd I was told she had developed an infection in her wound where the fractured hip had been pinned. I visited her on Monday 24th, at 3pm. She was just being wheeled back into the ward after having her dressing changed. A very concerned male charge nurse said she had green pus oozing from her wound. He said they would be treating her with antibiotics. 'She has an infection,'

he said. He wouldn't say what it was, just 'an infection.' He looked very unhappy at what he had to say next. 'The infection has grown because it (the wound) was wet,' he admitted. Since the staff continued to leave her in a urine and faeces soaked bed or incontinence pad then it was not surprising. This was obviously the direct cause of her infection.

A swab was sent for analysis. Imagine my shock when, on Tuesday 25th August, the same nurse admitted they still hadn't had the result of the test. 'It takes three days to get the results back.' From a lab in the same hospital? Incredible. In the meantime my mother had not been treated with any antibiotic - not even a broad spectrum antibiotic - and was in dreadful pain from the infected wound. Up until this infection the distress and pain had been from her extreme 'nappy rash' and bed sores. Now her distress was beyond endurance. You cannot possibly imagine the anger and distress I felt.

That same Monday afternoon I noticed one hand and her fingers were very swollen. I asked the nurse what was causing it. 'It would suggest she has renal problems.' I managed to get her to take a few sips of tea, water and 3 grapes, but that was all she'd take.

Again, not surprising she had renal failure. On a previous afternoon I'd arrived to find a nurse in her side ward, about to take her temperature. Mum was crying out, 'I'm so thirsty, water, water, I must have a drink.' But the nurse said briskly, 'You'll have to wait a minute, I have to do this first.' After taking her temperature she wheeled her apparatus out of the room, ignoring Mum's desperate need for water. I had to administer it myself. There was no way she could reach the cup herself.

On Tuesday 25th August, after seeing my mother, I had a case conference with a staff nurse and my mother's consultant. She's always had a healthy appetite and couldn't believe she'd not want food. 'We can't forcibly feed patients, rules forbid it,' the nurse said. The Dr added, 'You can come in at mealtimes and feed her yourself if you want.' Travelling all the way from Hollesley three times a day isn't an option, and surely it's a nursing task to make sure a patient is fed properly in order to build up their strength? Maybe there does come a point when people like my mum just won't eat, but I saw that whenever I came in and took the time, she would.

I was told she would not be allowed to discharge my mother back to a Residential Home but only to a nursing home. I should ring my mother's social worker and arrange to meet her the following day to discuss the arrangements and fill in the necessary paperwork.

I rang the hospital's social worker team and asked to speak to my mother's social workers early on Wednesday morning. I was told she was on the ward. I left a message, plus my contact details, with another member of staff, asking that she call me back as soon as she returned. At 1.30pm I had heard nothing so rang again. I was outraged when I was told that she had returned from the ward, hadn't bothered to return my call to arrange a meeting, and gone on holiday until September 3rd! I told the person in Social Work I'd already written two letters of complaint to the Chief Executive and had hoped I wouldn't have to write a third. What indifference to the patient in her care. She must have known Mum's discharge was being planned. I wondered if it was just me who is experiencing this level of non-caring in the hospital. I thought not.

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My mother died, I was informed by a duty nurse on duty, at 8.30am on Thursday 27th. I am the only local relative she has and I live in Hollesley. My sister, Susan Harvey, lives in Sussex. At 8.15am my sister rang me to say she'd had a call from the ward telling her Mum had taken a turn for the worse and she should come up. She was about to leave home for Ipswich – a journey of some three hours.

'Why haven't they rung me?' I asked her. She didn't know. This call from my sister was the first, and only time, I'd heard my mother was very, very poorly. I arrived at hospital at about 9.15 to be told Mum had died at 8.30. 'Why didn't you ring me? I wanted to be with her when she died.' The nurse's only excuse was that when the day staff came on duty they noticed she'd deteriorated and then called my sister.

Why didn't the night staff notice? Why wasn't I called? Had my sister not called me I would never have known. What on earth are the staff in that ward thinking of? Imagine my distress at finding I was an hour too late when I could have been there. Or perhaps she died earlier and the staff didn't like to admit they hadn't noticed?

I believe that Ipswich Hospital's report of to their inquiry into the three letters of complaint I made was a total whitewash. It did not address any of the really important questions raised, skirted around the issue of poor nursing and chose, instead, to deflect the blame onto me by saying I'd 'bullied' my mother. On the contrary, I loved my mother, cared deeply for her and her welfare and was desperate to get her away from the hospital and back into the residential home in Hollesley, a short walk from my own home, where I knew she would be loved and cared for by truly dedicated staff.

9. Louise Jacob

By her daughters Deborah Jacob & Rebecca Mencattelli

Our beloved mother Louise Jacob led an interesting and active life having worked at Elstree film studios when she was young and then for the probation service later in her career, while also bringing us up on her own when her husband left her. She worked full time up to the age of seventy, but still managed to fit in voluntary social work and being a member of St. Johns ambulance. Mum was very active and fit and took up running at the age of seventy forming her own running club. She loved gardening and nature and supported several charities. In her seventies a bad back and breast cancer slowed her for a while, but she managed to see off the cancer and had an operation on her back. Family was very important to her and she cherished her six grandchildren and was a surrogate grandmother to her friend's children. As well as family she had a close circle of friends whose company she enjoyed.

She suffered a stroke at home on her own on the 19th. January 2010 and was discovered thankfully by a kind neighbour and friend. She was taken by ambulance to the stroke unit at the Mid Essex Hospital Trust's Broomfield hospital in Chelmsford, Essex. She was paralysed down the left side, had lost her swallow reflex and had difficulty talking. Our mother had been suffering from a bad back for a long time and had a bad cold before the stroke so she was run down. We were informed that mother would have a scan in the morning and a nasal tube fitted in order to feed her.

The next morning when we arrived at the ward we discovered that Mum had not had her scan and the excuse given was that the porter had not turned up to collect her. It appeared that no one had thought of finding out why or chasing the porter up. The nasal tube had not been fitted either and

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the reason given for this was that they were short of staff. After a protest from us the tube was fitted later, but we were informed there was no pump available, but a porter had been sent to try and track one down. The porter never arrived with one. We argued that a specialist ward which received many patients without a swallow reflex should have a supply of pumps on hand. It was 48 hours before a pump was fitted.

When we asked why our mother was not receiving fluids as she was obviously dehydrated (we pinched her skin to prove it), we were told that "we [the nurses] can't stand here all day administering fluids" and "your mum has only been here 24 hours so what do you expect". When we asked if they had considered putting her on a drip an argument ensued, but eventually mum was put on an IV drip, but to add insult to injury they could not find a giving set initially. We also noticed that Mum had not received her aspirin or antibiotics. One nurse said she had been given them orally and another nurse said that as she couldn't swallow she hadn't received them. After all these complaints and queries the staff became defensive, irritated and hostile towards us with one nurse stating that "we can't do everything" and "your mum is not the only patient on the ward".

This was our introduction to the stroke unit on the first day which did not give us any confidence that mother would receive the treatment she deserved and was entitled to. From this point we kept a detailed diary of events, something we would recommend others doing if they become worried about the standard of care.

The next five weeks proved to be a catalogue of errors with poor basic nursing and treatment, poor record keeping, evasive and non-committal information and pure indifference and hostility by staff. On constant occasions Mum did not receive her medication, or the medication had not been noted down on the records so that the nurses couldn't tell whether she had received the doses or not. We had to ask that she was put on a vibrating mattress and wear stockings to avoid thrombosis or bed sores. When we asked for her to be moved in her bed during the day we were told to do it ourselves. Virtually every day her buzzer was put out of reach on the wall and her bedside table put on her left side where she couldn't reach it. She was often not given a bed pan and when she did was left for long periods propped on a bed pan. We found her one day very distressed and crying having been left in a chair for hours cold and in pain from her back. She had been left there waiting for the physiotherapist who hadn't turned up. Mum complained of something stuck in the roof of the mouth which turned out to be a build-up of phlegm. Although her mouth should have been cleaned every 4 hours no one had bothered. Although Mum could communicate if you had the patience and time to listen, it appeared the staff did not bother. Nurses did not provide accurate information on her condition when you telephoned the ward or pass on messages of good wishes.

After 10 days our mother's condition deteriorated and blood tests were taken, the results being lost for a day. She had a build up of fluid on her chest around the lungs which made it difficult for her to breathe. The draining of the fluid kept being delayed over several days and was finally done late at night when she was weak and tired.

Two weeks after being admitted and a day after we had arranged a rota of family and close friends to visit her and keep her talking and her spirits up, the hospital closed all the wards to visitors due to an outbreak of norovirus. Our hearts sank as we had no confidence that Mum would be looked after without us to intervene on her behalf especially as the Doctor had just informed us that her condition was worsening and she was not willing to open her eyes as though she had given up. On

asking whether the staff could guarantee that our Mother would not die before we could see her again, the Sister allowed a five minute visit adding she would get the sack if anyone found out. After that we spent days pleading for visiting rights and trying to speak to senior staff without success. Finally after 10 days the Doctor in charge of Mum intervened and arranged a meeting with the Matron who immediately said that common sense should have prevailed and of course we could visit our seriously ill mother.

When we finally got to see her we were shocked at how much she had deteriorated. We found her mouth in a mess again and her cannula site dirty and bloody with congealed blood. She was weak and depressed and it was very upsetting as she probably could not understand why we hadn't come and visited her. We will never know for sure whether her condition would have worsened as quickly even if we had been with her, but after what we had witnessed in the first few days we are all worried that she was neglected.

Six days later our mother slipped into a coma from which she did not recover and she died on the 22nd February 2010 at the age of 78.

The indescribable heartache and anguish caused through us not being allowed to visit our mother when she was lucid will be with us for ever as it will be for her close friends who never saw her after the second week. The hospital has apologised and stated it was never their intention to stop visits to seriously ill patients, but this has only compounded our anger and grief and we can never forgive the Broomfield Hospital for the way Mum was badly let down during the last few weeks of her life. It was not fair on someone who did so much good during her lifetime and had such a large circle of close family and friends who wanted to spend time with her.

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10. Megan Davis

By her daughter Heather Donovan

My mother Megan Davis, aged 83, was admitted to Gloucester Royal Hospital in mid October 2009 for a planned bowel operation. At the time she was mentally sound and fully conversant with the medical procedure to be undertaken, and determined to have it.

Though very hard of hearing due to a form of deafness called Menieres disease, family members had talked everything through with her and she seemed clear about her decision. She wore two hearing aids which were not entirely successful, but did give her a small but vital amount of hearing.

The surgical team was great and Mum's operation was completed without incident.
After being in the hospital for about 24 hrs, she came through the operation well and was sitting out of bed on my visit and was holding intelligent conversations. She particularly mentioned that she was looking forward to seeing one Granddaughter who was returning home shortly from Chile to see her. Her grasp of the situation was perfect. There was a menu in the single room for her to choose what to eat the next day, and we filled in her selections for her as she suffered with arthritis, especially in the hands.

Mum's friend, a retired nurse, visited her during the afternoon and instantly realised that the saline drip was not working, and reported it to staff. Later that evening, the drip still wasn't working, so it was reported yet again. The next day Mum was moved to a main ward, but the person serving food would not give her anything because, we later learned, the "nil by mouth " sign had not been removed from her bed. No one took the time to look straight at her and explain the lack of food, and the situation was exacerbated because she could see other patients enjoying their lunch and dinner. By now she had a water infection and a high temperature, she became agitated, was hungry and thirsty. Each time her temperature was taken, one of her hearing aids was removed and not properly replaced. Mum couldn't replace them herself because of the arthritis in her hands. It wasn't long before one hearing aid was lost completely! My Mum had waited 5 years. to receive digital hearing aids and was incredibly careful not to lose them, yet one was soon lost in hospital.

As various staff members came into contact with Mum, it became clear that none had any idea she was deaf, or how to behave toward a patient with this disability. As most looked away when speaking, she had no idea what was being said, causing her confusion, distress and ultimately agitation. Mum began to behave in a way which was completely out of character for her - shouting

that she wanted food and drink - so the solution was to move her to a single room different from the first one, without addressing the real problem. This confused her even more. She was then moved to a different main ward, and then again to another, different single room. She had no idea where she was or what was happening to her by this stage with all the different moves and the water infection making her unwell.

On one visit my mum's friend, the retired nurse, found two other patients' records on Mum's bed, all with the same surname. When she took them to a staff member, the reaction was simply, "Oh, I've been looking for those! " without any sense that getting people mixed up in hospital can lead to dangerous mistakes happening.

Often the saline drip wasn't working, and having had no nutrition for 10 days, Mum became more and more disorientated. Even her surgeon tried to feed Mum one lunch time as Mum was losing weight fast! It was decided to feed her by drip. A line was put into her stomach, but no nutritional supplement given because " no one had brought the bag up." On one occasion there was no nutrition because no one had taken it out of the freezer, and Mum had to wait hours for it to defrost. Not the best treatment for a vulnerable, now frail, elderly patient.

Mum could drink fluids, but only through a straw with assistance. This only happened when she had visitors who could help her. Mum had taken Nitrazepam on prescription for about 40 yea rs. and this was immediately stopped on admission. Could this have contributed to having hallucinations and talking gibberish? She was no longer in the real world!

Eleven years ago, Mum had an operation for breast cancer when lymph glands were removed. She was instructed never to have drips/blood/ injections in her right arm. This was pointed out to staff who routinely used her right arm regardless. Eventually, at our request, an alert bracelet was fixed to her wrist. When this was ignored the information was also written above her bed, but few noticed. When a needle was inserted in the correct arm, it was inserted so close to her elbow that it bent when she flexed the arm! It was eventually removed.

Mum then contracted pneumonia, and six weeks after the operation we were called back to the hospital, about 90 minutes after leaving one Sunday evening, as Mum was failing. We and other family members returned immediately, and once the family was there that Sunday, Mum was abandoned by staff. She spent a dreadful night, coughing and choking, struggling to breathe. We asked for something to ease her discomfort and she was given paracetamol.

The next morning a registrar offered morphine which we agreed to be administered immediately. It took half an hour to be given. The palliative care doctor arrived and arranged that the morphine be given automatically through a pump. An hour later Mum's urine bag was almost overflowing, and still no morphine pump had been set up. I asked a nurse to empty the bag. He came in with protective gloves and emptied the urine bag, and proceeded to administer the morphine whilst wearing the same gloves. This was witnessed by four family members. We were so stunned and shocked by his thoughtlessness that we were unable to speak. It was as if Mum was no longer a person because she was dying. Twenty nine hours after we were called back to the hospital, Mum died.

I realise I cannot change the way hospitals treat the elderly as this has become obvious through recent reports by different organisations throughout the UK. Hundreds of families seem to have made complaints and have met with indifference. However, I hope I can change the way deaf people are treated. In the workplace, provision is made for the disabled under the "Disability Discrimination Act," but it seems hospitals are exempt. Surely the old fashioned thermometers could be used if patients wear hearing aids? The cost would be minimal, or nothing at all. It would save having to remove the aids, ease discomfort and even make it less likely that such vital equipment for the deaf be lost. Is it also too much to ask that when talking to the deaf, hospital staff look directly at the patient? This would cost nothing and might even improve recovery rates. All that is needed is a little thought and common courtesy. My mum deserved better.

11. Patient A

By her daughter

The following is an account of Patient A's first experience of hospital care.

My mother's health had already started to decline before my father died. Memory and mobility problems were noticeable before 2006. After my father died she became more and more reliant on family and carers for day to day living.

After two falls in October 2009 she was admitted to the Princess of Wales Hospital in Bridgend for tests and observation. This was the first time my mother had stayed in hospital, having been in fairly good health for most of her 82 years.

We (her family) received conflicting information concerning her condition and future care. She had a fracture of the hip/ she did not have a fracture. She had a chest infection/she had a urine infection. She needed EMI care/she could go home – It depended on who we managed to speak to. If the family were confused, then my mother most certainly was greatly confused.

During her stay at this hospital she was moved 4 times between wards. Staff were too busy to help her walk to the toilet – it saved time to either wheel her or bring a commode – also, to be on the safe side, incontinence pads were used. I think this combination is part of the institutionalisation of patients and the reason my mother became incontinent.

On December 20th at a family meeting with the geriatric specialist and social worker we were told that my mother could go home the following day. This was obviously impossible to arrange at such short notice – she would need four care visits a day, special equipment put in place, not to mention arrangements with medication and pharmacy visits. It seems rather harsh, but at this point we thought she would be safer where she was until after the holiday – it took some persuading for staff to see the sense in this.

On December 30th (just 10 days after we were told she could go home) at a meeting with the medical physician we were told that it would be unlikely that my mother would go home unless she had 24 hour supervision and encouraged us to look for a placement in a residential home. She stayed at the hospital until the end of January – we were hoping she would at least not be moved now until a place was ready for her, but bed-blocking (always a problem) necessitated a move, in the interim, to a community hospital – Maesgwyn.

February to April saw a further decline in my mother's mental health. The following statements constitute facts (while hopefully avoiding opinions) contained in a letter I sent to Abertawe Bro Morgannwg NHS Trust in April 2010.

During her stay at Maesgwyn my family mentioned to all levels of staff that Mum's needs were not being met satisfactorily, but because of the rigid, institutional atmosphere we were concerned not to compromise her care by complaining too much.

She was not bathed or showered frequently enough – this was very noticeable to visitors.

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She was left to her own devices in the toilet – she couldn't cope with incontinence pads and was seen on one occasion walking in the corridor with her underwear and pad around her lower legs – very distressed.

Underwear and clothes that were soiled with faeces and urine were left in her wardrobe – resulting in the clean laundry smelling and possibly being contaminated. On reporting this to a senior nurse, the reply was that she couldn't be present all the time to prevent this.

My mother was left without her denture until recently (October) because in February a carer inadvertently threw it away. It's been left up to her family to arrange a replacement.

It was very difficult for brief 'out of hours' visits to be made by relatives who, for example, work unsocial hours. Mum's grandson was only able to see her on rare occasions because of his shift pattern. A little flexibility, even just to exchange laundry and say 'hello', would benefit the patient and relative.

There is a pleasant patients' conservatory where visitors can sit with patients – but only if staff are not taking their break or having meetings. I and other family members were asked to leave on more than one occasion.

In conclusion, my mother's first experience as a patient has been very unfortunate. At this point I must express an opinion - the general atmosphere and attitude of Maesgwyn Hospital is one of 'institution'. Staff have a tendency to close ranks. Some patients I spoke to were afraid to complain. Having said that, some staff genuinely cared for and comforted my mother – and I'm grateful to those professionals.

Mum moved to a residential care home in April 2010. She took with her an undiagnosed urine infection (diagnosed 2 days after the move) and black mould between her toes.

Although myself and my brothers bought my parent's house for them 12 years ago, we no longer have enough evidence to prove this, which means of course, my mother is self-funding. Her home has been taken over by the Social Services.

The care home is part of a large group – Hafod. It is new, spacious – doesn't smell of boiled cabbage/pee. My mother has a lovely en-suite room. One thing she would really benefit from is a view that doesn't look out onto a brick wall. We've been promised a change of room for her since May. Her care, in the main, is very good – there are still some condescending attitudes towards vulnerable people who don't speak back – or if they do, they're considered troublesome. One example of a major problem which affects dignity and respect concerns the laundry arrangements – clothing disappears. A month ago my brother received a mobile call from the home on a Saturday afternoon which initially alarmed him. It was a senior carer asking him to bring more underwear in because my mother had none and was uncomfortable in paper knickers. Mum took 12 – 15 pairs of briefs, mostly new, in with her clothing in April – her name was marked on them all. When I was there 2 days later I was invited down to the laundry to look for them. There was no choice but to take some random pairs because everything was in one muddled pile. Suggestions have been made to keep residents' laundry separated by various methods, but they've gone unnoticed.

Consequently, my mother now wears other people's knickers.

Myself and my brothers have always respected our parents. Only so far we can go with my mother now – we have to trust the 'professionals' to uphold this respect and carry on when we're not with her to maintain her dignity and comfort for whatever time she has left. She pays a lot of money for her care, which at times does not seem to cover the dignity and respect she deserves. I'm only aware of the issues I see when I visit – I'm not aware of what happens when I'm not with her.

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12. Joan Louise Hilleard

By her daughter Lisa Cumbers

Throughout her life, my Mother had always led an active life. She had never been ill nor had she ever taken any medication – not even paracetamol, she didn't believe in them! The day before her stroke she had been to Sevenoaks on the bus to get her shopping. At the age of 63 she became a Tourist Guide in Canterbury for the Canterbury Tales attraction and she was also a Friend of the Royal Academy of Arts, travelling to London on the train to see exhibitions.

After my father died in 2001 she rebuilt her life and became an active member of village life in Kemsing where she joined the craft club and cleaned the brass in the village church of St Mary's. She was also a member of the Kemsing Heritage Society and went on many trips with her friends.

I will always remember her happy, smiling face, her love of the countryside, gardening and knitting. She was there when my twin boys were born and helped me stay positive. We talked everyday on the telephone – something I miss greatly.

She was loved by all her family and friends and many villagers expressed their sadness when she died .They were shocked at the way she had died and said she was one of the kindest ladies and didn't deserve to die this way.

On July 19th 2009 my Mother was admitted to Princess Royal University Hospital, Farnborough. She had woken up on the Sunday morning feeling ill and she was also unable to move her right arm and her vision was disturbed. She had managed to call me, as she lived on her own and I rang the doctor who told me to ring for an ambulance which we did.

After she was admitted on the Sunday evening I was informed that she had indeed suffered a stroke and was transferred to the stroke unit.

To begin with, I thought she would recover and I also went with her to watch her have physiotherapy. It became apparent that she was doubly incontinent as well. She would not eat even in the early days and kept saying that she had a metal taste in her mouth and everything tasted funny. I looked this condition up on the Stroke Association web site and they said that stroke can affect taste. At this time I was desperate for information and it was not forthcoming from the stroke unit at the hospital.

I was horrified at her deterioration during the past few weeks as it seemed to me that she was actually starving to death. The nursing staff I understand are very busy so I offered to come in at lunchtime to try and tempt her to eat. I was also worried that she was not in command of her faculties and vulnerable. I am a teaching assistant and was on six week's holiday so I had the time to do this but my offer was never taken up. I was beginning to get very angry because the staff on the stroke unit rarely communicate with you, not even a greeting. All the time I was waiting for them to approach me to discuss my mother's condition but they never did.

I was approached by Social Services and was told to look for a nursing home for my mother but I was unable to do this because I did not know the extent of my Mother's condition so I wrote a letter to the consultant caring for my mother asking for an explanation and I also told him that my Father had died from a stroke in awful circumstances and therefore I was anxious for it not to happen again to my Mother. I was also concerned that more serious medical conditions had arisen because of the lack of fluid and nutrients in the early days. I felt more could have been down to help her eat.

On Thursday 3rd September 2009 I asked a nurse if I could speak to the consultant who was sitting at the Nurses' station and I asked him if he had received my letter. I was with my 16 year old son and there were also nurses and doctors witness to our conversation. He said that he hadn't received my letter and was very abrupt and humiliated me in front of his colleagues and my son. I was upset on the day because I was watching my mother, who I have cared for since my Father's death eight years ago, starve to death in front of me. He told me that if she wanted to starve to death then it was up to her and that he wasn't force-feeding her. I told him that I wanted to know about the extent of her condition and he told me that I had no legal right to this information and he wouldn't discuss it with me. He kept saying that he wasn't treating me. I also told him that I had applied for Lasting Power of Attorney and he categorically said that I would not get it. He then said aggressively that we were talking about 'end of life 'and his job was to 'relieve suffering not prolong life' and that he could do as he pleased (carte blanche). I thanked him for his time and told him that I was taking the matter further and as you can imagine I was in considerable distress. I think the way he spoke to me was insensitive and unprofessional.

He should have offered to take me into a side room to discuss the matter, diffuse the situation and calm my anxiety. Instead he carried out the conversation in full glare of everyone around us.

The encounter left me feeling afraid to speak to anyone on the Stroke unit. When my father was in Sevenoaks hospital his consultant was very kind and took my mother (next of kin) aside and explained that he only had a couple of months to live. I think this helped prepare my mother for the worse. I thought that this was the procedure in hospital (advance care planning). This did not happen to me. Doctors should note Paragraph 29 on Good Medical Practice from the GMC (see copy). I have also read the Department of Health National Stroke Strategy, the NHS End of Life Care

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Programme and the Royal College of Physicians National Sentinel Stroke Audit and they all say that the feelings of relatives/carers of stroke patients should be taken into consideration, a practice sadly lacking during my mother's time in hospital.

My mother died on the 12th September 2009. We were informed at 3am Saturday morning on the 12th. Nobody asked if I wanted to see her body. We were told to collect the death certificate on Monday 14th September 2009 but when I arrived I was told it was unavailable because a post mortem was to be done because the doctor did not know the cause of death – a wasted journey. The Registrar and Coroner's Office were very sympathetic to my plight.

My Mother's belongings were collected from the bereavement office and we were upset to find her belongings screwed up in a bag with juice cartons, and her hair still in her hairbrush. Nobody asked if I wanted her wedding rings removed or where they were.

I am not seeking compensation; all I wanted was to be included in my Mother's care – I felt I was being persecuted because I cared about my Mother's welfare. I feel that I could have given the medical staff some valuable information that could have helped my Mother's condition. I believe the reason she wouldn't eat was because she was doubly incontinent and what went into her mouth had to come out and she was embarrassed by this. I did mention this to one of the nursing staff but nothing came of it. It seems that if a patient does not improve then they give up treating you.

I wrote a letter of complaint after my mother had died.

In their response the Trust said that the because of the "clinical workload of the nursing and medical staff, they would not routinely speak with all relatives who visit the ward." I hope they realise that on a busy ward you can feel intimidated and it might help if at least to start with staff at least introduced themselves and let visitors know they were happy to answer any questions.

They wrote that the ward sister had spoken with me "on the 30th September with regards to your mother's meals." My mother had died on the 12th September.

They said the doctor was sorry for upsetting me and agreed he "did perhaps respond in an abrupt manner, however he felt your approach was confrontational." He also accepted he should have spoken to me privately.

I am not normally a confrontational person. I had witnessed my father die on a hospital ward in very similar circumstances to the ones my mother was in at the time. I wanted desperately to help her. I would've hoped doctors and nurses could understand this.

They explained that they couldn't "force" my mother to eat and drink. Of course I know this, but I don't think they ever really tried. I was there when I could during visiting hours and tried to encourage her, and if you took the time it helped. I worry for a patient without a relative who can come in and help. When I visited my mother there were often yoghurt pots or juice containers with the foil lids still on. If I had not come in that's how they would have remained. Taking into consideration that my mother was paralysed in the right arm I think this was cruel and unacceptable. And whilst I was told by some staff to come and help feed her, others told me not to. My husband's colleague's Grandmother was in the stroke unit at the same time and they felt the same.

I wrote back again and they said they would look into the specific concerns about the doctor. That was almost a year ago and I haven't heard from them since.

I hope in future other relatives and carers are not put through the same experience as my family and I have been and in future they are treated with sensitivity. My Mother did not deserve this and the memory of the look of fear in her face will remain with me for the rest of my life.

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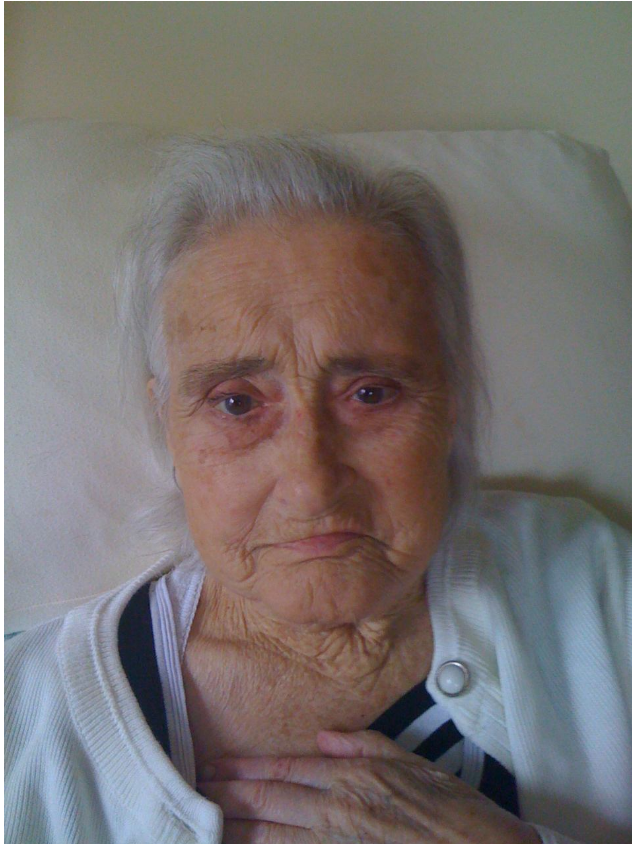
13. Elizabeth Cavanagh

By her daughter Patsy Dowsett



My mother was born on the 19 July 1921 to an East End family, she was the second eldest of 9 children born to my grandparents. Two of my mother's sisters died in infancy. My mother never married and I have no brothers or sisters, it was just me and my mum.

My mum joined up during the Second World War as she wanted to be a chauffer, however they had other ideas and she was assigned to be anti aircraft gunner. She survived the war and numerous bombings including the Bethnal Green Tube disaster.

My mum went over to America when she was 26 years of age in 1947, but she only went to see what America was like; she returned several months later - she was a feisty brave young woman.

My mother was a top machinist for a company called 'Maxell Kiddie Clothes'. When they moved their head office to Peterborough the company offered to buy my mother a house so that she could still be their 'top' machinist. However, my mum's family ties were too strong and she stayed in London.

My mother set up several companies and never gave up on her dream of being self employed and owning her own business. In fact when mum was 66 years of age she opened up her own café. It was a great success with the workmen until she retired in her mid seventies.

My mother never gave up on life, she instilled in me that you could be anything you wanted to be if you really wanted it.

Every year we went on holiday together. When I divorced my first husband mum would look after my children so that I could go back to work and have a career (I worked my way up to be a consultant in Local Government and carried out various assignments travelling around England from London to the borders of Scotland. I see no point in anything now. I have no mother now, no mother to talk to, no mother who would show how proud she was to others concerning me and my career (but never to my face), no mother who was so happy that she had 3 grandchildren.

She was always there for the family, her brother and sisters, nieces and nephews and her grandchildren - for me. I just cannot seem to move on from what happened to my mother in hospital. I have nightmares about Queens and how my mother must have felt, so lonely, so scared and in so much pain.

My mother was admitted to Queens hospital on the 16th November 2009 when the care home she stayed in became worried about her condition. I and my husband visited mid day and evening. My mum looked perky, alert, she looked well and she had a nice colour to her skin tone. The visit went well as we talked and chatted and my mother asked me to bring her in some home made food.

We came back in the evening and brought home made vegetable soup and cream caramel – mother said she had just eaten. Another patient informed us that the food had been placed in front of her but she did not eat it and no one helped mum to eat or drink. Mum ate a few spoonfuls of soup, drank some tea and blackcurrant drink and ate her cream caramel. A care assistant tried to transfer my mother to another ward whilst she was eating her evening meal (the food I had brought and I was assisting my mother in eating). I told her to come back when my mother had finished her meal.

At approximately 7.15pm mum was transferred to another ward. Shortly after she arrived my mother wanted a bed pan. I spoke to a nurse who did get a bed pan and placed mother on it, pulling the curtains round. I left the cubicle to give some privacy and then the nurse then left. My mother finished using the bed pan and started calling for help. When I looked in through the curtains my mother was in what looked like a very uncomfortable position (like a turtle on its back) and her nightdress had been pulled completely up to her waist and she was fully exposed.

The nurse did not return and I went to find her. I found her chatting to other nurses at the nurses station/ward reception. I say chatting as the nurses /staff, were not discussing patients or hospital procedures etc., they were laughing and joking. I explained to the nurse who had placed mother on the bedpan that my mother had finished but she did not end her private conversation/chat.

I went back to my mother and waited for another five minutes – all the time my mother was calling for help – I then walked past the nurse's station/ward reception, where the nurse who had put my mother on the bed pan, was still chatting. On seeing me as I walked past her and the other nurses, she then said (as I overheard her) 'that I best get back to ....???? (I did not hear this part) whereby she and the other nurses laughed at her remark/comment. I continued to walk out of the ward

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through the security doors and went to try and finds PALS to complain. When I returned to my mother's bed she had by this time been taken off of the bed pan.

The next day I arrived at lunch time – the call alarm buzzer was back in the holder on the wall, out of mum's reach. Mum wasn't hungry but I tried to tempt her with some homemade soup and she ate a little.

The food servers hadn't left her pudding so my husband went and got some from them –my mother ate about 2 spoons of pudding. My husband was concerned and so he spoke to the nurses, and requested that my mother be given her nourishment drinks which she has in the home. Mum had only 2 of these given to her and always at our request. They did not give them to her as part of her normal daily diet regime.

My son visited his grandmother later in the afternoon. She was asleep and he asked the nurse if his grandmother had been given her medication and pain killers. The nurse would not answer him, she would not give any kind of response but went off to other patients. He had to follow her and demand an answer which he still did not get.

As his grandmother was asleep he decided to leave – the same nurse reproached him by questioning why he was leaving. He explained that his grandmother was asleep and he did not want to disturb her. This nurse tried to put him on a guilt trip – totally unacceptable. She commented "You have not been here long, why are you going?", sucking between her teeth.

The next day I arrived at 12'ish with food for mother, walked to mother's bedside as she was in a very uncomfortable position, she was on her side and both her hands were clinging to a bar at the side of the bed. The Nurse Alarm was in the holder on the wall again out of my mother's reach. My mother's lower half of her body was exposed. The nurse had just gone off and left her like this. I covered my mother so that she could keep her dignity. The other patients on the ward informed me that my mother had been left like this for quite some time.

I went and found a care assistant and asked for assistance in putting my mother in a more comfortable position. This person told me that it was not her that had left my mother in this way. However she did come to my mother's bedside and assisted me in getting my mother into a more comfortable position.

I then went to nurses' station/ward reception and found 4 members of staff there, 3 nurses behind station/counter and one in front. I explained that I would like to talk to someone regarding my mother. One of the nurses asked for my mother's name and who I was. I gave them this information and asked what my mother had been eating and who was monitoring this?

They then said 'were you asked to come to the hospital?'

To which I replied 'no'.

They then said 'that visiting was at 3 pm'.

I then said 'really, I know that my mother has not been eating, I have been bringing her soups to eat. Who is monitoring what she is eating or drinking? What is the prognosis for my mother and when will she be allowed home?'

To which the response from the same two nurses, was a noise of sucking in air between their teeth and they said 'When she looks like you and me'.

I really did not know what to make of this comment and the time at the nurses' station was only about 3-5 minutes. It was all so quick. On reflection could they have been referring to the fact that my mother and I are white and that they were black? I do not know but at the time that these comments and actions were made my brain was just screaming "who are these people, why on earth are they making such nonsensical comments?" I could not really believe what had just been said and their actions whilst they were making their comments. My reaction to this was a startled 'what?' and they repeated 'When she looks like you and me'.

I was totally amazed by their behaviour and for a few moments at a loss for words at what they had said. I then said 'well that is never going to happen is it'. To which they said 'do not put your mother down'. To say I was in total shock and so worried for my mother at that moment is an understatement. I was flabbergasted and deeply, deeply afraid.

I reiterated that I wanted to know 'who is monitoring my mother in what she is eating and drinking, what is the prognosis and when will my mother be allowed home?' and that I would be at my mother's bed waiting to find out.

I then went back to my mother and the other patients in the 2 beds opposite my mother informed me that my mother had been calling for assistance in the night and wanted pain killers – but she was ignored by the nurses and staff. They also told me that my mother had not eaten and that the nurse who was supposed to be washing her that morning just walked away and left my mother exposed from the waist down and in an uncomfortable position.

On being told this, I explained to my mother that I would be popping out for a little while but that I would be back. As I walked past the nurses' station/ward reception the same nurses were still there laughing and joking.

I phoned my son and husband and explained the above. I then went to PALs and explained the above. They contacted a Matron. My husband left work and arrived at the hospital at approximately 1 pm and the Matron met with us at approximately 1.15 pm. We explained what had happened, and also what had happened on the night that my mother was transferred to Sky A ward.

The Matron gave background information regarding the ward and the staffing issues. This ward was recently opened without its own staff yet and so they were using agency staff. But ultimately that is not our problem – the problem is that the nurses were not carrying out their basic duties, and therefore were not carrying out their duty of care and as such my mother was being neglected and ultimately abused by nursing staff on at Queens Hospital.

The Matron gave re-assurances that this would not continue and her contact details including her phone number should we have any further problems.

That Thursday evening my daughter visited her grandmother at approximately 7 pm. On arriving the other patients on the ward informed her that her grandmother had been calling out as she was in pain., that they (the patients) then called for the nurses for my mother as my mother was being

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ignored by the nursing staff, they asked the nursing staff to give my mother pain relief, but they were also ignored. Plus when one of the other patient's sons had visited he also tried to help my mother get pain relief. He went and found a nurse and also asked that they give pain relief to my mother as she was in pain – the nurses ignored him.

On hearing this my daughter went to one of the nurses but this nurse said to my daughter that she was too busy and sent my daughter to another nurse My daughter went to this other nurse, who was very hostile towards my daughter. The nurse was totally ignoring my daughter by not acknowledging her and not making eye contact with her, the nurse was trying to alienate my daughter by not being open to her , her body language was closed as was her lack of communication. My daughter had to literally walk her to my mother. My daughter was persistent in this as she knew that if she did not get this nurse to her grandmother at that time and get the necessary pain killers for her grandmother now this nurse would not bother with her grandmother when she had left after visiting.

This nurse was asking my mother questions (who was 88 years of age and in great pain) 'was she in pain?' My daughter answered for her grandmother – the nurse ignored my daughter, this went on for a few minutes. The same question was asked 3 times and 3 times my daughter answered for her grandmother with the nurse ignoring her response.

The nurse then asked 'where the pain was?' My daughter again answered for her grand mother to which the nurse said to my daughter 'I am asking her not you', my daughter replied 'and I am on my grandmothers behalf telling you where the pain is'.

The nurse then said to my daughter 'that sometimes people say they are in pain and they are not'. To which my daughter replied 'if my grandmother was not in pain I would not ask for pain killers for her, but she is in pain and she needs pain killers'. The nurse very reluctantly gave my mother pain killers.

The next day (Friday 20th November 2009) I arrived at hospital at approximately 1p.m. I went to the bed where mother had been but was informed by the other patients in the ward that mum had been moved. They didn't know why my mother had been moved, but thought that mum had gone to a side room. No one had contacted me to let me know this.

I went and found my mother in a side room. The nurse alarm was in the holder on the wall out of my mother's reach. My mother was in a disorientated state, her lunch was in a tray on her bed table, it had been untouched, was cold and congealed and it was fish. Mum was allergic to fish as it said in her notes. There was in the sink a washing bowl filled with bloody water and bloody guaze.

I spoke briefly to mum and then went to find a nurse to find out why mum was in a side ward and why she was given fish. I found a nurse and at the same time as arriving back at mum's room the ward assistant had taken mum's food tray from her bed and was in the process of disposing of the food.

I queried why my mother was given fish when it states quite clearly in her notes that she is allergic to fish. I also asked who was monitoring what she was eating and drinking as it was obvious to me that no one was.

I gave my mother the homemade soup that I had made as she was ravenous and gave her fluids to drink. I informed the nurse how much she had eaten so that she could make a note. I put on mums radio, volume on low and on the classical channel, so that she could have some background music for comfort.

After leaving I phoned the ward at approximately 4pm as I wanted to know why she had been moved to a side room. I was told that she had the some kind of infection but mum had been put on a course of antibiotics to clear this up.

That Friday evening my son visited his grandmother at approximately 6 pm and found her music turned off, the nurse alarm back in the holder AGAIN and his grandmother screaming for help. Her bed was saturated with blood from her right arm (soaked through the bed clothes). My son went to the nurses' station and asked for assistance.

No one came.

My sons fiancée went to the nurses' station to ask how long before someone gave pain relief to his grandmothe and to also look at her right arm which had bled through.

The reply was 'Soon'.

A nurse eventually walked in and said something along the lines of 'we will be with you soon darling'.

No one came.

My son's fiancée went back to the nurses' station and again asked for help and assistance.

No one came.

My son then rang the nurse alarm call buzzer to bring a nurse. A nurse walked in turned off the buzzer and said along the lines of 'will be with you soon darling'.

No one came.

My son after 1 ½ hours of watching his grandmother in pain, hearing and watching the nurses talking chit chat and laughing finally lost his patience. The nurses on this shift were still the day staff on duty – they did nothing but ignored pleas for help and assistance from my son, his fiancée and his grandmother who by this stage was actually quite incoherent with the pain.

The night staff came on duty and a nurse told my son that she would give my mother, his grandmother, pain killers and that she would clean her and her bed. She did start doing this some 2 ½ hours after my son requested help. She helped as soon as she was made aware of what had happened at the start of her night shift. She did try to help. It is the day staff who completely ignored and neglected my mother.

My son phoned me and told me what had happened. He was incredibly distressed by it all and of course I became very worried. I telephoned the ward and spoke to the same nurse who had helped my mother. She reassured me she would make my mother comfortable.

The next day I phoned at 9am spoke to a nurse and asked how my mother was. She retrieved my mother's folder and said that she had a good night and had eaten well. I then explained what had happened on the previous day and said I thought any information in my mother's folder on her eating and drinking for that day was pure fiction, it was not to be believed and I knew that my mother had been neglected for the last week. This nurse then passed me to the Duty Matron and I explained all of what had happened on Friday to her and she suggested that I speak to her today when I visited my mother.

I arrived at about 2 pm and spoke to the Matron. She allayed my fear slightly and I did feel a bit more comfortable that my mother would not be ignored over the weekend. She started a food monitoring sheet for my mother and after reading the notes said that a scan on my mother's stomach had been requested on Friday 20/11/09. I queried this as I was informed on 17/11/09 by the nurse in emergency ward that a request had been put in on that day, 17/11/09 for a scan on my mother's stomach. I asked why were there two requests and why had my mother not already had the scan?

On entering my mother's room the nurse alarm was back in the holder on the wall out of my mother's reach. I pinned it to her pillow.

The radio was not on, so I put on mum's radio on the classical channel, volume not too loud, so that she could have some background music as a comfort.

I asked the matron if my mother could have some physiotherapy as she had been left in bed for a week and she was getting cramps in her legs which were causing her severe pain. She said she would look into it. All appeared as well as could be, but mum was still in pain and confused.

The next day, Sunday 22ndNovember, I phoned in the morning to see if mum had a good night, was given assurances that she had but by now I did not believe anything that I was being told.

I visited at 2.30pm. My mother was out of bed and in a chair – hurray! Someone had actually moved her. She seemed in better spirits. I did note however that there was medication on her bed table that had not been taken.

I went to the nursing station to find out when my mother should have taken the medication that was left on her bed table. I was informed by senior staff nurse that she was not managing my mother's room.

I said 'OK, but I would like to know when her medication should have been taken?'

This senior staff nurse then pulled my mother's file and said the medication should have been taking in the 'morning'.

I then questioned as to who should have given my mother her medication?

She replied 'that it was an agency nurse'.

I then asked to speak to the duty matron.

She arrived quite quickly andsaid that she had spoken to the nurse who had failed to give my mother her medication and she apologised. I was starting to think that apologies didn't mean much.

We discussed all of the above and when it would be feasible for my mother to be released from hospital – she did say that it would be the doctor who had been allocated my mothers' case that would ultimately be the person to say when my mother could be released from hospital.

My mother and I during this visit discussed the news and played word games. The radio was off so I put on mum's radio on the classical channel, and the volume not too loud, so that she could have some background music for comfort. The nurse alarm was back in the holder on the wall so I removed it from the wall holder and I pinned it to my mother's pillow before I left.

At about 4 p.m. the evening staff arrived and a nurse came and introduced herself to my mother and me. She seemed extremely caring and put my mother at ease straight away. I felt very comfortable when I left at 4.30 p.m. knowing that she would be caring for my mother.

The following day I phoned in the morning and spoke to a senior male nurse regarding mum –I was told that my mother had a good night, I did not believe him. I asked to speak to a doctor and he said he would see what he could do for when I was visiting at 2pm.

I arrived at the hospital and spoke to the same male nurse with regards to seeing a doctor. He said that he had asked and that the doctor would see me when he started his rounds later that afternoon.

I asked the senior male nurse if my mother had had any nutrient drinks and could she have plain broths, custards etc, nothing that she had to chew. He said that he would arrange for drinks and bring in soups that had extra nutrients in for my mother. This never happened.

I walked into my mother's room and her bed table was awash with needles, water, blood and material of some kind (a small patch of bloody gauze). I fetched the same nurse I had been talking to earlier and showed him. He started clearing the mess.

My mother was in bed and in constant pain – she had not been moved. The nurse alarm call buzzer was back in its holder on the wall out of mum's reach again. I took it out of the holder and clipped to mum's pillow again so that it was within her reach.

The radio was not on again so I put on mum's radio on the classical channel, volume not to loud, so that she could have some background music as a comfort.

I tried to feed mum with broth that I had made and brought in. She ate a few spoonfuls and then said she wasn't hungry. She had a few sips of blackcurrant drink. We played word games. Mum was in pain, I requested pain killers. The same scenario was played out again with nurses ignoring my mother's cries of pain, my pleas, the buzzer. This went on for some time and she was eventually given painkillers some hours after request, but only after severe distress to my mother and myself.

Whilst waiting for the pain killers for my mother at about 3.30pm I asked the nurse when I would be seeing the doctor. He said he would check. He did not come back to me.

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At about 4.30pm I asked the same senior male nurse when I would be seen by the doctor. He informed me that the doctor had started his rounds and would see me later. He did not get back to me.

At 5pm I asked the same nurse when I would be seen by the doctor. He informed me that the doctor was doing his rounds and would see me when it was my mother turn to be seen. He did not get back to me.

Considering that I had initially been told that I would be seen when the doctor started his rounds and that I couldn't see any other relatives wishing to see the doctor I am somewhat at a loss at to why the doctor could not and did not see me before he started his rounds.

I had to leave before my mother was seen by the doctor and during this time no nurses came into my mother's room to a) give her a drink or see what she had drunk (b) to see if she needed anything (c) to move her (d) to see to her wellbeing.

The next day, Tuesday 24th, I arrived at just after 2 p.m. I again requested to see the doctor, I again requested nutrient drinks and soups for mother, I again checked mum's folder and found it to be pure fabrication. The nurse alarm call buzzer back in the holder on the wall out of mum's reach, I took it out of holder and attached to mum's pillow. The radio was not on again.

Mum had a couple of spoons of my home made broth and a few sips of blackcurrant drink. Mum kept asking me not to leave her there. I had already been making notes and putting lines through pages of my mother's file so that nurses and staff could not put in fictitious information, for example that she had eaten and drunk, for if my mother had eaten and drunk she would not have dehydrated and lost weight, she would have also passed more urine and her bowels would have moved more often, my mother would not have deteriorated so rapidly if she had been given a proper nutritious diet – her file prior to this and I suppose after this was pure fiction. No one came to see my mother or me during the time I was with my mother, approximately 2 ½ hours. Mum eventually dozed off and I left, still without seeing doctor.

The next day I couldn't visit and none of the family could. I deeply regret not visiting on the 25th as the following day, the 26th, when I visited, mum looked like she was dead but still alive, screaming in pain, incoherent, clinging to the bed in a foetal position. She wouldn't/couldn't eat or drink. I could not touch her as she screamed in pain.

The nurse allocated to my mother was ignoring my mother's pleas for help. Nurses, care workers and doctors, were walking up and down the corridor and sitting at the various work stations. No-one I repeat NO-ONE was attending my mother. I could hear her screams as I was walking to her room, and when I went into her room the nurse alarm was back in its holder on the wall out of my mother's reach again and the radio was switched off.

I was frantic –I did not have a mobile phone and had to go to the waiting area on that floor to use the public phone to telephone my husband and son. Whilst I was making these telephone calls I was also banging my head off the wall. A member of the public was very concerned for my well being as I was totally petrified and totally out of control of my feelings. I did not however, as some would have done, scream and shout at the staff as this does no one any good, plus what would happen to my mother when I wasn't there if I did scream and shout at them? I suppose on reflection nothing more

could have been done to her by them as they did nothing for her anyway. I telephoned my son and husband – My son arrived first and just could not comprehend how my mother, his grandmother, had deteriorated so rapidly since they had last seen her.

I spoke to the Matron, senior male nurse and doctor. I asked for intravenous drip so that mum could get some fluid into her.

I took mum's file to PALS so that they could see the lies and fabricated information that had been entered in my mum's file. Whilst I was with PALS a doctor had put up a drip in my mother's arm but luckily my son was with my mother after he had left and not checked on her as she had an adverse reaction. He called for help. Her arm ballooned up where the needle had been put into her lower part of her arm. My son said it was like someone blowing up a balloon, but it was in nanny's arm.

My husband then arrived and when he saw my mother you could see he went into shock he just could not believe what he was witnessing.

My husband, son and I were trying to get mum to drink but she could not so we then wet tissues and were wetting her lips and squeezing the tissue in her mouth so that she got some fluid into her system.

No one was helping my mother or us, we were just left. It was like the staff were avoiding us and did not want to look us in the eye. In fact I will say that they were avoiding us, I think I can guess why.

My mother was in constant pain calling for help, the doctor eventually saw mum and then spoke to us.

They were going to transfer mum to a different ward that night. The doctor stated that prior to examining my mother he did not hold out much hope for her survival but after examination he was confident that she would survive but be very frail. I requested an air bed for mum as she had been left in one position so long by staff on the ward and the Matron said she would organise this.

During the time my mother was on the ward a dementia patient wandered freely around the wards. On several occasions I had to bar her way as she attempted to enter my mother's room. My mother was totally incapable of defending herself from this person should anything untoward have happened. To allow this dementia patient to wander freely around the ward is totally unacceptable. The same dementia patient on several occasions went through patients' files, including my mother's, which were left outside their rooms – this is totally unacceptable.

My mother moved to the different ward and I went to visit her lunch time. I was challenged by a member of staff who I believe was a nurse. She did not want me on the ward and was very hostile towards me. She would not listen to me and went off to get the sister/matron. They were not empathetic. They were in fact quite inhumane about it all. The nurse did not want me on the ward during lunch time, even though she knew what had happened in Sky A. She said there should be no visiting during lunch time unless you have been allowed by the matron or consultant. As I was allowed to visit during lunch times and evening meals with my mother on Sky A I did not see why I could not on this ward. I think that they just wanted to use their little bit of 'power'.

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I was forced to leave; I went to PALS to express my concerns.

I returned during visiting hours. My husband and I made sure my mother was drinking and made notes in the file of how much she drank. Mum was starting to look like her old self when we left – it is surprising when someone is actually given food and water how much they improve in their appearance.

I visited with her the next day with my husband as before, helping her to eat and drink, making her comfortable.

The next day (Sunday 29th) was the day when I first noticed the bed sores to mums feet as previously mum had been wearing bed socks. Mum asked me to lift up the sheet and fan her feet as they were hot. I duly lifted the sheets and screamed (involuntary scream) as I then saw the condition of my mum's feet – I honestly thought that she had gangrene (as I had never seen bed sores before).

No wonder mum had been in so much pain, needing help and frequent pain relief.

I didn't realise at the time how serious it was, and a sign of real neglect, that these bed sores had been allowed to develop and get so bad. It was only when mum was later discharged to the care home and they reported them that it sunk in.

We called the nurse, who then called a senior and they then made a note of the area of bed sores on mums feet – they actually said that she must have come into Queens on Friday 27th November 2009 and into their ward with the bed sores. I pointed out to them that mum had been in Queens since 16 November 2009 and had been transferred from inside the hospital to their ward, and that it was in the hospital that she had got into this state.

It was obviously very apparent at this stage that the staff on the ward had no idea that my mother had in fact been in the hospital for 10 days prior to her being moved to their ward, and this led to my husband, my children and me making the assumption that no notes or files on my mother were passed from ward to ward, or if they were, they hadn't been read.

We encouraged mum to drink and made notes. Mum was talkative and in a cheerful mood. We left mum comfortable and in a good frame of mind.

For the next two days we visited mother and she seemed better and they were looking after her properly. On Thursday 3rd December 2009 she was discharged. After deciding that they wanted to stop her medications in hospital, her discharge letter said that they should be continued. They obviously realised their mistake at some point. They sent a fax, an approximate 5 line scribble, giving information that my mother Elizabeth Cavanagh was not to receive any medication. The Care homes nurse on receipt of this fax telephoned Queens to ascertain if the information on the fax was indeed correct. The nursing staff at the home were extremely concerned regarding this instruction from Queens as they were fully aware of my mother's ailments, i.e Chronic Heart failure etc. The nurse tried every day on numerous occasions to speak to someone at Queens regarding this but no one at Queens would talk to her or return her call.

I was told about this only on the 8th December. The Nurse asked me if I knew of this fax and its contents. To which my response was a 'no, I was not aware of this information'. On receiving this

information I immediately contacted the Complaints manager at the Trust and telephoned the Chief executive at Queens and spoke to his PA.

I also sent a letter dated 14th December 2009 concerning this matter. A meeting was organised between the doctor, complaints manager, my husband and I, which we had on the 16 December 2009 and notes of this meeting were forwarded to me first by the Doctor. I read through these notes and noticed that they had omitted some very pertinent facts. I had to telephone and explained the facts that had not been included. They had failed to put in the part where the consultant admitted that he had read the wrong notes.

Sadly Mum was readmitted to hospital as an emergency on the 19th of December. She was very very unwell. The paramedic told us that mum had had a stroke. When we arrived it took over 4 hours for her to be transferred from the trolley onto a bed. When we were with her in the emergency room we asked for chairs so we could sit with her, but we were told there weren't any.

My mother passed away at 8.30 a.m. Monday the 21st December 2009. We informed the nursing staff and they brought in the doctor to certify that my mother had died. We, the family, left my mother. We left her fully covered and she looked asleep, her legs were covered, her arms were on top of the bed clothes and her eyes were closed – she looked at peace.

However, my son would not let me back into the room immediately after the doctor had carried out her examination and left as he had some idea what she was doing and how she would leave my mother and unfortunately he was right. The doctor had exposed my mother's left foot and left it dangling and exposed. She had also opened my mother's eyes and left them open. My son who is very thoughtful went into my mother first and put her foot back onto the bed and covered her exposed limb. He then closed her eyes.

This doctor showed contempt for my mother, for me and my family by leaving her the way she did. I am extremely upset by this and the fact that my son who was distraught had to go in and prepare my mother after this callous person had carried out whatever test she had to do. This doctor did not talk to us as a family, she just walked off.

The death certificate said my mother died from a "myocardial infarction", a heart attack, not a stroke as we had been told.

Our family complained to the Trust, explaining everything we had tried to raise whilst we were there.

They sent an intermediate response which disputed some of our claims, but admitted that the nursing care was inadequate. They said that the ward had been opened and agency staff used before the regular nurses were in post. They have said it was mismanagement and that they wouldn't do it again. But how do I know this? Who is going to check? And who is going to check that other Trusts elsewhere aren't doing the same thing?

The doctor that left my mother in such an undignified state after death was apparently new and very regretful at what had happened. They said she would be spoken to about it and if anything similar

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happened she would be disciplined. But that is what they said about the nurses when we first told them things were awry.

And what has been done about the nurses on the ward that were so unpleasant? Has the hospital reported them to the agency? Have they been struck off? I didn't know about the Nursing and Midwifery Council before contacting the Patients Association. How many other people should be reporting nurses but don't know they can?

The safeguarding team carried out an investigation because of the pressure sores which were reported by the care home. The investigation report said that Queens On the balance of probability all agreed that there was a delay in the chart being implemented, **which indicated neglect**. On admission to hospital Elizabeth Cavanagh should have been assessed using a chart 6a within 6 hours according to NICE guidelines. All felt that this would have implemented plan of care to support EC. This would have also detailed the turning regime.

My mother should have been supplied with an air mattress and the safeguarding team also stated that, as she was not supplied with an air mattress, on the balance of probability, this **indicated neglect on the part of the** hospital.

My mother's diet and nutrition should have been monitored and the correct foods and drinks should have been given to her. The safeguarding team also found that all in the case conference agreed that on the **balance of probability there were elements of neglect.**

Clementine A ward provided much better care than Sky A ward. Staff on Clementine A ward were more engaging, caring and recording thoroughly. The family believe that there was a blatant difference between the care received by Elizabeth Cavanagh when on Clementine A ward compared to Sky A ward. The family added that Sky A ward appeared understaffed. The family felt that Clementine A ward were more organised and person centred. EC's family described EC as appearing dishevelled during her stay in Sky A ward.

All in the case conference agreed on the balance of probability **that there was neglect on part of this particular ward SKYA.** BHRUT advised that they will be looking into these concerns.

For all reasons mentioned and judged on a balance of probability, all in the case conference agreed that the allegations raised in the alert were substantiated.

Other contributing factors to the pressures identified included EC's legs being flexed. As this would have affected the blood flow (as advised by TVN-WK) all agreed on the balance of probability this would have been a contributing factor to the accumulation of pressure sores.

There were concerns that EC was not eating properly which all considered on the balance of probability would have also affected the care of the pressure sores.

During the case conference the family voiced concerns regarding EC not being provided with the correct diet or services of a dietician. All attendees agreed on the balance of probability ***that this indicated neglect,*** *Barking, Havering and Redbridge Hospitals Trust advised they would be looking into these matters.*

The police were contacted for their stance on this case. She advised that it would be a criminal matter if it was an individual who had the sole care of the patient. As it appeared that this was the failing of the institution as a whole, they advised that the institution should investigate their own failings.

The safeguarding team stated that because there appears **to have been more than one incident of neglect** one could argue that there is a high risk of these events re-occurring and therefore the Safeguarding Adults Investigation recommendations should be strictly adhered to.

I must add that I was not aware that an independent investigation was being carried out by the safeguarding team. It was just by chance that a member of the team contacted me by phone to see if I would be interested in going along to any meetings regarding their investigations. At the time of the call I was in a very, very low state of mind and did not know what to do. I could not see the wood from the trees so to speak. I grabbed the chance of this opportunity to finally get some justice for my mother with both hands. I attended said meeting and subsequent meetings.

When I received their final report I was sent back to that dark place again as every time I read it I want to scream out in pain. My mother , my poor defenceless lovely mother went through so much pain and neglect in a place where she should have received the best possible treatment. My mother was let down by the NHS, when she needed them the most. She was let down by something that she believed in and supported all her life.

I cannot bring my mother back, but WE can and WE must make sure that this never, never happens to any one again. They are answerable to US. There should be no more of the NHS closing ranks and keeping on board negligent staff, be they consultants right the way down to cleaners. They should be either struck off or dismissed NEVER to work in this field again.

Every time I try to do something for my mother I am taken back to that terrible time, and I go into a very scary place, where I cannot see any light or any reason. It takes me weeks if not months to get back to some kind of normality. I am lost without her and do not know what to do. I want to make people accountable for their actions and I do not want this to happen to anyone again.

My mother did not deserve to be treated this way and did not deserve to die in this manner.

All I can think of is that we will eventually be back together again, I hope, as none of us knows what happens next. I hope and pray that my mother started a new journey and that she is with her loved ones, her mother, father, sisters, aunties, grandparents her family and that she is happy and at peace.

I unfortunately am not and I do not know when I will be.

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14. Albert George Edwin Battey

By his daughter Ann Frost

My father, Albert George Edwin Battey, died in Princess Royal University hospital on 30th November 2009 aged 85. I have also had to allow myself time to come to terms with the circumstances leading up to his death, and the traumatic effect it has had on me. I don't have a complaint about any particular individual; rather I hope that someone will take steps to remedy some of the "caring" faults within the NHS.

My father was a quiet, shy man, who found it very difficult to speak up for himself, even though it was obvious to us that some of the care he was receiving was not good, and he was suffering. He was always fussy about his appearance, kept himself clean and tidy, and during his working life he always gave priority to his family's well-being, and never claimed any benefits, and indeed we struggled to persuade him to claim the Attendance Allowance that we knew he was entitled to in the latter months of his life. He did not serve in the Second World War, but he later did his National Service and spent three years serving in India in a "peace-keeping" role. So I consider that he always paid his dues, and that the NHS let him down when he most needed it, and indeed until he reached the age of 80 he had little need for medical treatment.

Since 2005 my father was receiving various treatments for prostate cancer and also heart related issues. In 2009 his health progressively deteriorated, resulting in him spending periods of time in hospital in April, September, and finally from 8th to 30th November when he died.

In early April 2009 my father collapsed at home with breathing difficulties and was admitted to Princess Royal University Hospital. Around the same time, my mother was diagnosed with breast

cancer, (aged 82) requiring a mastectomy. My mother had surgery on 14th April in Orpington hospital and was discharged on 18th April, she then stayed with me for a week, and during that time I had a call from a social worker I believe, who was adamant that my father had to be discharged even though she was advised that my mother was not back at home, and not fit to care for him.

My father's discharge was (thankfully) delayed due to an infection, and he was eventually sent home on 28th April, but before that we were called to see this same social worker as she wanted to set up a care plan. Hoever there was no room for discussion about this, all this "person" wanted to do was "tick boxes" on a form, and she didn't care at all about the extremely traumatic circumstances the whole family was facing at that time. After my father came home the care "package" fell apart. It was less than useless due to (some) badly trained, clumsy and unreliable carers. As an example, mother often had to struggle to clean the commode herself as it wasn't cleaned properly. My mother decided she was better off without the carers, even though she was still trying to come to terms with the shock of her operation, and recovery from it.

My father's second stay in hospital was last September 2009. At the time I thought it was related to his warfarin levels not being managed properly but I was never actually told what was wrong with him. The sight and the dreadful condition of his arms (they were black and seeping blood) at that time is something that still haunts me to this day. I do not know how or why this happened or who was responsible for monitoring his warfarin, but on looking at his record cards, there seemed to be a gap of around a month in the dates around that time. In their response to a complaint I made after my father had died the hospital said his blood was too thin but said it was because of "acute kidney failure" and he had been admitted to treat this.. They didn't explain whether waiting from August to October was normal practice. I don't think that my father ever really recovered from this set-back, and needless to say he went home in a far weaker and worse condition than he was previously.

My father complained to me during his spells in hospital last year about staff handling him carelessly and causing him great pain (the skin on his arms was very fragile due to effects of steroid drugs). He also suffered falls during his stays, sometimes unavoidable, but once due to a careless incident (on medical ward 9) with a bed rail, which collapsed and caused him to fall. This caused further damage to the skin on his arms and legs, the injuries were bandaged but little attempt was made to treat these or even change the dressings, even though at one point the consultant was heard to ask for them to be changed.

He complained to me on one occasion that his knee was very painful, and on looking at it I could see that the bandage had slipped down and the skin around was extremely red and angry looking, and must have been causing him absolute agony. He also had bandages on his wrists which hadn't been changed, and again were causing pain. I went outside the room to look for a nurse, but no-one wanted to help, and I was actively ignored by three nurses who refused even to make eye contact with me, although though they didn't seem terribly busy at the time. Eventually a young male nurse said they were "monitoring" the injuries, which I felt was totally inappropriate. After further requests from other members of the family the dressings were changed, but this is simply not good enough. This all happened on medical ward 9, which was the ward he died on, and which was like a "ghost town" at weekends as far as staffing was concerned.

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During his stays in hospital my father needed toilet facilities, but was not always given help even though staff seemed to be available, with resulting "accidents" at which I was present on occasions. I remember going to see dad on one occasion and he said he needed to pass water. I was present when he asked, he was just told "don't worry about it" which meant he had no choice but to wet the bed. I was appalled. My father was a very quiet but very dignified man. For him this was the ultimate humiliation. His distress and embarrassment and humiliation were painfully obvious to me and extremely upsetting. Abuse is a two-way thing, there are notices everywhere in public places these days saying it will not be tolerated, but I felt intimidated by some of the staff in the hospital, and I felt afraid to say too much in case my father suffered for it. I also felt that my father was suffering abuse by way of some of the poor care he was receiving. This is surely not right.

My father also complained more than once of having plasters "ripped" off his arms where he had cuts from falls etc, causing the most unbearable pain and further damage to his fragile skin. I cannot begin to imagine what that must have been like for him, and wonder why on earth plasters were used when bandages might have been a kinder option? He also complained about "clumsy" man-handling by both porters and nursing staff sometimes, causing further tearing to his skin and more bleeding and pain. I cannot understand this as it was very obvious to all of us just how fragile the skin on his arms had become (due to effects of steroid drugs).

There is another issue of my father's missing watch. I have had a reply to my letter from the patient relations manager about this. I agree that the watch was not locked away, but my father used to wear it so it shouldn't have needed to be, it was only when the skin on his arms became too fragile that he started leaving it on the table. The watch had no great value, but was very sentimental to me as it was the last thing I bought him, and that was only a few weeks before he died. Sadly it seems it disappeared on the day he died.

On the day my father died my mother and I were making a routine visit but that day I could not park the car, so I told my mother to go ahead and I would look for a space but it took me about 40 minutes to park. During this time my father sadly passed away very suddenly. I realise that no-one could have predicted that, but it was very traumatic for my mother, and I wasn't there. When she realised what had happened, she tried to summon a nurse using the call button, but found it was tied up out of reach behind the bed (why?), so my father would have been totally incapable of calling for help anyway even if he had been able to. My mother went to call a nurse, and she said there was an initial "panic" reaction with several members of staff involved, and then nothing. They just left her there on her own with my father, with a nurse just saying she would try and look out for me, which didn't happen. Surely someone could have stayed with my mother until I arrived, and also lessened the blow for me?

My mother told me that when she arrived to see my father on the day he died he didn't recognise her, so there must have been signs that all was not well and someone in the nursing profession surely should have realised this, and maybe we should have been called, but we weren't. After my father died, no-one made any attempt to make him look more comfortable, and he was left in a "sitting-up" position, eyes left open, which just didn't seem right or fitting or respectful, and not a pleasant memory for me to have as it was the last time I saw him.

My father's final weeks in November 2009 were spent on medical ward 9 in Princess Royal University Hospital, as he was admitted to casualty prior to being transferred to this ward. I understand that this ward is one of these "assessments" wards connected to casualty units, and from reading matter in the national newspapers, these wards are apparently used to "manipulate" hospital casualty target figures. I have to say that this ward was not a good one for my father to stay in, it was one of the worst and some of the care he received was appalling as I have mentioned previously, and sadly he had to die there as well.

I spoke to a nurse the week before my father died, as during the whole time of my visits, no-one ever attempted to give me any information about my father's health or prognosis. The nurse advised me that according to his file he had three months at most, but it was obvious to me, although I do not have nursing experience, that he was not going to live that long. However, despite this, I understand that the consultant, who was responsible for my father's care, told him the week before he died that he was going home! We, as a family, already knew that was no longer an option. It was very obvious to us that my father would not be able to cope at home any more, he was far too frail and ill, and we had already made it clear that if he had to be discharged he would have to go into a nursing home. I regard that consultant's words as callous, uncaring and insensitive.

In the week following my father's death, I had to have one of my dogs put to sleep. At our vet's we were treated with nothing but kindness and compassion, and the vet took her time to discuss the situation with us without any need for "ticking boxes". My dog died peacefully in my arms, with quiet dignity, and no pain, fear or suffering. My father did not have the benefit of this; he was absolutely terrified in the last few days of his life. I couldn't ask him why, he didn't have the strength to tell me anymore, but I feel sure that his fear was connected with being in the hospital, and some of the treatment he was receiving. I was unable to be with my father all the time, so there must be other incidents which I am not even aware of, and I very much regret that my father was unable to ends his days in a hospice, where I think he would have received a much better standard of care, compassion and dignity.

My late father-in-law was in hospital back in 2001 (Queen Mary's, Sidcup) with a broken femur following a fall. His initial stay there was in a completely empty ward, in which he had a bed with no headboard, and no locker, just a plastic bag on a chair to keep his belongings in. My own most recent experience with the NHS last year was at Maidstone hospital (I had a knee problem requiring assessment by a rheumatologist), where I was more or less told to "shut up" by a consultant for trying to be too helpful or so it appeared, and then told that he would make his diagnosis based on the contents of my GP's letter. I hadn't asked to see a consultant, my GP referred me, but he made me feel I was wasting his time and that it was my fault. I went home feeling very let down, and just hoped that my knee would not give me any further problems, as there is no way that I would ever want to see that consultant again.

In 2005 I worked on a care-line handling emergency calls from elderly, disabled and vulnerable people living in the community. I left this job after six months because it was run as a call centre, with too much emphasis on the speed and number of calls handled by the operator, and I felt that this was a totally inappropriate way to deal with vulnerable people.

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I wrote a letter of complaint to the hospital in February this year and it took until September for them to send me their response. There was a delay whilst they asked for and then I sent a consent form from my mother to allow them to investigate a complaint lodged by me which they received in March. They wrote to me on 19th April 2010 advising that the investigation was taking longer than expected because the Trust was restructuring. I wrote again on the on 24th May, crossed with theirs of 21st May explaining again the delay was due to restructuring, but they hoped to respond shortly. I wrote again on the 29th June chasing a response again. They replied again on the 12th July with the same answer as before but also said they were waiting for information from the phlebotomy department. I sent a further letter on 4th October chasing reply yet again. This crossed with their letter of 28th September in which I finally got a reply. I was never given any indication as to when I would receive a response from the hospital.

I feel that I owe it to my father, and anyone else who finds themselves in a similar situation to take part in this report in the hope that someone will take notice and take steps to ensure that all patients, including elderly and vulnerable ones, are given a decent standard of care, especially in the last weeks of their lives. I also owe it to friends I have spoken to, who expressed regret that they did not write about their experiences with hospitals when their loved-ones died. I am not saying that all hospital staff are bad. But there is an element of arrogance and egotism with some consultants and doctors, who seem to be accountable to no-one, and indifference towards patients and relatives from some of the nursing staff.

Anyone who works in the medical profession should only do so because they care about people, and if they don't they shouldn't be doing it. Nursing should always be about care, compassion and empathy, and staff also need to be able to communicate on a much more approachable and friendly level with relatives of patients. It is no good having these modern "flagship" hospitals such as Farnborough if the staff do not come up to standard as well, and maybe the recent issue of hospital cleanliness has compromised equally important care issues.

In the newspapers recently there was a case of an elderly couple who were found dead in their Northampton home, as a direct result of no-one in the "care" system doing anything about their plight, despite calls from worried members of the public, and this does highlight a concern of mine that all these "agencies" are not working together when dealing with vulnerable people. They are just doing their bit and "passing the buck" with little concern that there is often poor liaison between them. My mother did not know whether she was coming or going sometimes with all the staff from all different organisations that used to arrive unannounced at the house, sometimes causing undue stress and worry. My parents also had an unscheduled visit from "someone" who told my father that he needed to make a living will. This was handled very tactlessly, it upset my parents greatly, and the visit should have been arranged via a younger member of the family (both parents in their 80's at the time) who could have made this experience (if it was really necessary) a little less traumatic for them.

Patients are not about "targets" and "ticking boxes" they are about living, breathing human beings who suffer pain and fear like the rest of us, and in the 21st century in which we now live, no-one should suffer poor treatment in hospital or anywhere else, especially if they are obviously nearing the end of their lives. The NHS needs to go back to the days of being a caring organisation, but sadly I think that has long gone.

15. Irene Schneider

By her son-in-law Colin Yeo

We have spent every Christmas and birthday with my mother-in-law since 1975, except 1979 when she went with Pop to visit their son in South Africa. When she could hardly move and was in terrible pain with the cancer she said 'you have been more than a son to me you have been a friend and have given good council'. To describe mum as my mother in-law does not convey the right relationship.

Rene, as we all called her, was a very happy, gregarious lady who loved company and was loved by many. She lived for six years with her family and during that time she attended Day Care Centre four days a week and went by taxi once a week to the Over 60s club at the local British Legion where she played cards and joined in with all activities. She would always have a laugh and a wicked joke. She attended all family celebrations: weddings, birthdays, Christmas etc. and would often go with us to have lunch with her grandson and his family. She was affectionately known by her great grandsons as "Nanny Rene".

The family have always taken notes on mum's health to keep an eye on possible problems slowly occurring.

She had bowel problems for several years. The symptoms included severe pain, distended stomach, infection and frequent trips to the toilet.

She had been admitted into hospital as an emergency, on a number of occasions, because of these problems. Gallstones were diagnosed on one occasion but were not removed because of her age. The Consultant recommended a low fat diet to prevent flare-ups.

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In May 2009 Rene was very poorly and was admitted into the Royal Devon & Exeter Hospital. We were told that they didn't expect her to last the night. Subsequent tests were inconclusive but to the best of our knowledge no MRI or Cancer indicator tests were done.

Whilst she was in hospital it was almost impossible for mum to get a low fat diet. 90% of the nursing staff didn't know the fat content of basic foods and thought that low fat mayonnaise contained little fat and that Flora was fat free!

We noticed that when a nurse was asked how Rene was doing they referred to a small hand written note they kept in their pocket. When we asked how the note was compiled we were told the handover nurse gave the information to them from the previous shift.

On the 4th December 2009 Rene had a fall whilst going to the toilet in the middle of the night. About a week before the fall we noticed mum was under the weather and we took her GP who had treated her for a urinary tract infection. She was taken into the RD&E by ambulance. Ten minutes later we followed mum to the hospital but we were told she was not there and had probably been taken to another hospital. From previous experience we knew that they often delayed entering admission details we believed to help meet their targets of patient time in the A& E.

The Doctors who eventually saw her in the A&E authorised two X-rays but could not see any fractures. An OT came to assess her and tried to get her admitted to a Community Hospital but due to a lack of beds she was admitted onto an ENT ward in the RD&E.

Rene was given large doses of painkillers and, we were told, laxatives to counteract the effects of the painkillers. She was still in a lot of pain but daily an Occupational Therapist came to mobilise her. The OT said that there was nothing wrong with her but she lacked confidence to walk. Often it was necessary to hoist her in and out of bed. The hoists are like a motor mechanic's engine lifter. It looked and was very uncomfortable for Rene, not to mention very embarrassing for an elderly lady in just her nightdress!

Rene was moved about six times during her stay at the RD&E and about 50% of that time she was in wards with the Norwalk virus and not allowed visitors. Not only was her mobility restricted but also she didn't have any social stimulation.

On Christmas Day we had not been able to visit her for about two weeks because of ward closures. We decided to visit even though we had been told she wasn't allowed visitors. We found mum eating her Christmas Lunch. This consisted of Steak Pie with puff pastry topping with roast potatoes and vegetables. To follow she was to have Christmas pudding with clotted cream and cheese and biscuits. So much for her low fat diet!!!

While we were there the meals were passed from one NHS staff outside to another inside. They wore sterilised gloves but one auxiliary sneezed into a small paper tissue, wiped her nose, threw away the tissue and picked up the next meal for a patient. There was no glove change or hand wash.

This was typical of staff understanding of the spread of infection. A little later a staff nurse on the isolated ward was wearing sterilised gloves whilst working on commodes, another nurse asked for some keys and the first nurse put her contaminated gloves into her pocket and passed the keys to

the unprotected nurse! Her pocket, the keys and the nurse asking for the keys are now all contaminated.

Towards the end of December they wanted to discharge Rene but she was effectively confined to bed and in a lot of pain despite the painkillers. I contacted the PALs Unit when I could not establish which Consultant was responsible for her care. The PALs Unit managed to discover her Consultant was in Australia on holiday and another Consultant was asked to investigate. The first Consultant never communicated with the family and didn't reply to phone calls via his secretary.

The new Consultant, authorised X-rays and a fracture was discovered. Despite the reluctance of operating on a 93-year-old lady a short operation, using an epidural, was done early on Saturday morning on the 30th Dec 2009. This Consultant was very good and communicated well with the family. Her leg slowly got better but we were worried that her progress was hampered because of the first month of no treatment, high levels of morphine, laxatives and being bed bound.

During her stay she had lots of stomach pains and the nurse on duty would say that a scan had been organised to investigate. When you asked the next time it would be a different nurse and they would not know any information. We discovered that each ward has two files on each patient one on the bed and one at the ward reception.

Whilst Rene was there she was often found to be dehydrated. One day when we visited we thought that she was dying and after trying to wake her for several minutes she was very confused and did not recognise us. The nurse had told us before entering her single room that she had been moved the night before and that she was having a nice snooze. We recognised the problem and after giving her several drinks she was sat in bed talking and looking "normal". We asked the nurse on duty to make sure she was having plenty of fluids and she agreed. Before we left we put a sign above her bed asking for her to have her fluid intake monitored. The next day when we visited she was again dehydrated and when we asked the nurses, chatting at the workstation, we were told that they were too busy to make sure she had been drinking!!!

During her stay at the RD&E her toe nails were 12mm overgrown and despite many attempts to get them cut we were told there was no podiatrist in the RD&E to cut them. Unfortunately the nails were cutting into adjacent toes and were making any chance of mobility difficult.

Rene was discharged to the local Community Hospital towards the end of January 2010. On admission she had to be isolated because of an MRSA infection in her nose. This prevented any exercise or socialising and she was confined to a small en suite room. Their handbook said they were there to provide 14 days of care before discharge.

On the 2nd February 2010 (8-9 days after admission) we had a phone call from a "Volunteering in Health" Organiser, who told us Rene was being discharged to home on 5th February 2010. We visited her almost daily and she was also visited by other family members. We all knew that she was unsafe for discharge and was also not medically well. She could not stand unassisted, walk, get in/out of bed or go to the toilet by herself. She had diarrhoea (we were daily taking home soiled clothes to launder), abdominal pains and wanted to go toilet every 40 minutes day and night. Any assistance she needed required two attendants. She had also become very confused. When she had been admitted in May 2009 she was 12 stone 7 lb and was now about 10 stone 7 lb. This was all explained but to no avail. We asked who had made the decision to discharge mum and we were told the Deputy Matron, a GP and the Occupational Therapist.

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That afternoon we visited Rene to confirm our views and gather evidence to support our statements because we felt we weren't being listened to and needed to be able to prove it. We took photographs and short videos with a small camera as mum tried to stand and walk. There were no staff in her room while we did this and as it was a single room, no other patients.

That evening we phoned the Deputy Matron to explain our concerns. She repeated what the Organiser had told us. She said mum was well and ready for discharge. We explained that we had photographs supporting our views. She told us that it was illegal to take photographs in hospital. I asked for written confirmation of this.

The following day we contacted Care Direct and asked for an urgent referral. They said they would contact the Hospital and arrange a home visit. This was then arranged for the 9th February.

On 5th February we noticed that information on her toilet visits were not being recorded on normal record sheets but were being put on plain white paper with no official reference to her hospital number and no link to the main notes.

Rene was clearly unwell, looked yellow and weak in addition to her other problems. We went next door to the Health Centre and asked to speak to the GP in charge of her care. Unfortunately she was unavailable then but we did manage to speak to her several days later but we were told she was medically fit for discharge and our concerns were ignored.

On the 7th February the Deputy Matron found me using the camera in Rene's single room and demanded, in front of her, that I stop. Rene was very distressed. Reluctantly we managed to move the Deputy Matron out of the room to discuss. I asked once again for written confirmation of the rules. She said she would raise an incident report and it could result in criminal proceedings.

The next day I contacted the Information Governance Officer and the Pals Unit for NHS Devon and asked for a copy of the rules regarding the use of a camera in hospital. It appeared there were no rules or policy and the Information Governance Officer thought it was time to develop a policy. I also discussed access to medical records and the Information Governance Officer thought it would be a good idea if a nominated friend or family member had access to the patient's current treatment.

The Pals Unit asked if I would attend a meeting with the Matron and their Complaints Manager on the 9th February and I agreed.

On the morning of the planned meeting Rene had the home visit. An OT and her assistant arrived. The OT made it very clear that I was not allowed to take pictures of NHS staff. We agreed that they would keep out of view when necessary and I would not take pictures of them.

From the very start it was clear Rene was unsafe to be discharged home. She was very confused at where her rooms were and was unable to walk across the hall without having to sit down to rest. She found it very difficult to get out of her chair and was completely unable to get to her bedroom although on the ground floor. Also she left diarrhoea on the seat and floor of the toilet.

The meeting with Matron, the Complaints Manager, daughter and son occurred in the afternoon. We had been asked to prepare a list of problems, which had occurred with her treatment, but if it didn't involve this Hospital they were not interested.

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These are the things we listed to be discussed:

1. Problem with giving mum low fat diet
2. Keeping accurate records of mum's bowel problems
3. Access to mum's current medical treatment
4. The hand written notes on nurse shift change.
5. Policy of using a camera in hospital
6. The non-adherence to discharge procedures issued by Care Direct.

It was agreed

1. That mum would stay in Dawlish Hospital for a further two weeks (Done)
2. Mum would be referred to the Bowel and Urine clinic to investigate her bowel pains and diarrhoea. (Not Done)
3. Mum would be referred to the podiatry unit to cut her toe nails (Done two weeks later)
4. Complaints Manager agreed to send us the policy on the use of cameras in hospital.(Not Done)
5. Complaints Manager agreed to come back to us on our rights to access mum's current medical treatment (Not Done).

Both the Matron and Complaints Manager took copies of the family's consent form and Registered Lasting Power of Attorney for Health and Welfare. They said the information would be put on file so that there would be no need to reproduce them again.

A week later Rene's home GP phoned. He said that he had received a letter from a Consultant at the RD&E saying that there was a shadow on mum's lung. Her GP had also noticed that she was still on laxatives which should have been stopped when she came off the high doses of painkillers. He said unfortunately he was unable to treat her while she was in the Community Hospital but would write a letter to her GP at Barton Health Centre, Dawlish. We later discovered he got into trouble for writing this letter. The NHS we had discovered in the past has a very strict hierarchy and pride comes before the patient.

On the 18th February 2010 the Matron said Rene was to be discharged on Monday 22nd February. We asked for a home visit. We were told by Matron that she had already had a home visit. We explained that the visit had proved she was unsafe for discharge and insisted on a new home visit.

On the 24th February 2010 Matron and OT brought her home for another home visit. The family present included her daughter, son, son-in-law, daughter in-law (who is also Deputy Chair of another NHS Trust), Matron and OT. From the meeting until this visit we had not taken any more photos as we were trying not to generate further conflict with the staff. However Rene was still clearly unwell with the same symptoms as before and once again they were trying to discharge her. When Rene arrived home we started taking photos and short videos of mum trying to perform simple tasks such as sitting on the bed. The Matron was saying she was so well and that if she stayed in hospital she would pick up an infection. The OT stuck with our previous arrangement to stay out of view but when she moved into view, to help Rene, the Matron declared the visit was over as I had taken pictures of her staff. We put the camera away and persuaded the Matron to continue with the home

visit offering to prove that photos of the OT had not been taken. The home visit continued but was aborted later when it became clear even to the Matron that Rene was unsafe for discharge.

There was a deep discussion between the Matron and Rene's daughter in-law (Deputy Chair of the other NHS Trust) over the statutory requirements regarding Hospital Discharge. The Matron didn't agree with her statements.

All records had been removed from the end of mum's bed since the meeting on the 9th February and we were concerned about what was being hidden so on 26th February we wrote to the Information Governance Officer expressing our concerns at the lack of access to Rene's medical records and treatment even though we had the consent form and Lasting Power of Attorney for Health and Welfare. This letter which was both posted and sent by e-mail was never replied to and the NHS denied ever receiving it.

Rene was still not well and needed 24 hour care which we could not provide so on 3rd March 2010 she was discharged to a Residential Home in Exeter. She was still not well, her stomach was very distended and she needed to go to the toilet every 40-60 minutes.

Over two weeks later Rene had an emergency readmission to the RD&E Hospital because of the distended stomach and severe pain. The next day she was diagnosed with extensive bowel cancer, which had metastasised to her abdominal wall, liver and lungs. The Consultant said Rene might have months to live. An operation was performed to put a stent in her bowel to allow her to pass faeces. The hospital has three specialist cancer nurses to help the patient and family. We thought at last someone would listen to our concerns. Little did we know that they are impossible to contact when you need them.

Rene was discharged again to the Residential home. She was not well and had the same problems distended stomach, diarrhoea, pain killers.

A few weeks later she was taken in to hospital for X-ray. Her daughter went along to be with her mum and discovered her in hospital dehydrated and confused. Her daughter nursed her for hours but nurses were cross with her for asking for water, sick bowls and toilet pans. Rene was then readmitted because of her problems and the fact that she had not opened her bowels for five days.

The next day the nurse in charge of the ward phoned to ask if we would be home to receive Rene who would be arriving late morning. We told her we didn't think Rene was well enough to go anywhere, currently lived in a residential home and also asked about the results of the X-ray. She was completely flummoxed and when we asked for her name refused to give it initially saying she was only temporarily in charge of the ward.

Rene was not well enough to go back to the Residential Home and was moved to a privately owned Nursing Home, Sefton Hall in Dawlish about ten days later. Unfortunately Rene was under the Dawlish Hospital Doctor who refused to listen to us and had said she was so well. We were told she could not come under the family GP even though his surgery was only 5-10 minutes away by road. Our MP intervened and got our wishes granted.

The staff at Sefton Hall were second to none. The Staff Nurse in charge had a very simply philosophy to treat each patient as if they were her mother and used all her training and love to provide the best care possible.

Mum died comfortably several weeks later.

A day before mum was diagnosed with bowel cancer we received a letter threatening legal action for abusing the staff of Dawlish Hospital from an NHS manager. They said the filming constituted bullying and harassment of staff.

On 7th April 2010 we wrote a letter to the Chairman of NHS Devon Trust, asking for the letter accusing us of abusing staff to be withdrawn, an apology to be issued, and an independent investigation to be done into the allegations.

It was answered by a letter from the Complaints Manager stating she was the investigating officer. The letter requested a copy of consent forms which she had previously taken copies of. This was the same person who had taken our LPA forms in the first place. We didn't feel she should then be put in charge of investigating our complaint so we phoned the local NHS Trust to speak to the Chairman but had to speak to the PA of Deputy Chief Executive. She said she could understand my concerns and would try to ensure a fair investigation.

A letter from the complaints manager came stating that she could not proceed with our complaints about mum's care because she didn't have mum's consent even though we had previously given them a copy of the LPA.

The complaint about the filming was found against us by another manager who never contacted anyone outside of Devon NHS. They never interviewed us about what had happened. They stated that they did not have to prove we had filmed staff or others patients, the fact staff had reported we had was apparently enough. The exact words were:

"I do not believe there is a need to provide 'evidence of an offence' or to prove that you did take these pictures, for even if no filming was actually taking place you appeared to be operating a camera that was directed at staff."

We contacted her with regard to having a meeting so that we would have a chance to put our point of view to NHS Devon. When we asked to record the meeting, because we were concerned that earlier documents we had given them were apparently no longer in their records, they refused the meeting.

We approached our MP to help and as a result she received a response from Devon NHS Chief Executive. In the response it states we had no right to mum's records because we had not supplied a valid Power of Attorney, they said we had given an application for LPA. This is not true. The thing they ignore throughout this is that Lasting Power of Attorney is registered with the Office of the Public Guardian and it would have been easy for them to check at any time during the last eight months. That is why the Office for Public Guardian is there.

I still haven't had any investigation into the actual problems with care because they say I am not entitled to this information.

Through all this I would not like the public to think that all NHS staff are either incompetent or uncaring. Special thanks should go to the Orthopaedic Consultant, the Oncologist, the Social Worker and Rene's local GP.

My wife, Rene's daughter, wanted to give her perspective on what has happened.

Our whole life over that 8 months was consumed with mum. There was never a free moment when she was not in our thoughts.

If we were not visiting her we were contacting the NHS authorities to try to get her a proper medical diagnosis, worrying because we knew there was something terribly wrong. It was almost a relief when the cancer was finally diagnosed because we knew that treatment would follow to alleviate the pain she was in.

When we went though the ordeal with taking pictures we felt that we were fighting on all fronts- first and foremost to get treatment for mum but also from the NHS management who defend their staff's poor care by threatening Court action. We would not wish anyone to go through what has happened to us and hope by telling our story things will change for the better.

Additional Comment: The Patients Association contacted the PALS service at NHS Devon and explained that we were publishing accounts of patient care one of which related to NHS Devon. We explained that the account contained conflicting accounts of events and where possible we try to verify matters of fact if we can. We asked them to supply to either ourselves or Colin Yeo a copy of the "application for LPA" as it would confirm categorically whether or not Mr. Yeo had supplied an LPA. After two weeks we had not had a response from the Trust. A response was only achieved by contacting the office of the Chief Executive directly.

16. Stefan Jedrzejczak

By his son Stephen Jedrzejczak

DRAFT

My mother wrote to the Patients Association about the poor care and treatment she thought my father had received. In her letter she wrote.

"I feel very strongly that elderly people at the end of their lives need to receive the same care and consideration as anyone else. I also feel that all patients should be made comfortable, have their needs met and kept pain free."

Our whole family feels very strongly on this matter. We help people, we were not brought up to see others suffer and yet we feel we watched our father suffer horribly and unnecessarily. We don't think everyone who could easily have helped did everything they could.

My father was a gentle man, quiet and strong with an unbreakable strength of will. My father was always working, he was never sick, never missed days and when not working he would always be tinkering with something. When there was nothing for my father to do he would paint something; there was never anything in our house that needed painting for long.

My father loved cooking; he would always bake cakes and even later on when cooking was hard he would insist on always cooking the dinner. One of the few mistakes my father made was that he stopped putting extra sugar into his coconut cakes because it made them healthier, I liked mine with sugar, my father always made a good cake.

Every year in the summer we would end up somewhere on holiday. In a caravan by a sea, I have many happy memories of walking over rocks, going exploring, visiting markets, always something new. It was on one of these holidays in Felixstowe that dad took me to see my first wrestling match;

Dad loved his wrestling, with Mick McManus, Giant Haystacks, and Big Daddy being his favourites. He used to get so excited, jumping up and down and grabbing the air, you would think he was in the ring with them. Another love of my father was playing cards with his brothers. Every week on Tuesday, Valdi and Stanley his brothers would visit and spend the day playing cards. Even when Dad was very ill they continued to come and see him, just to keep him company.

All these lovely memories of a great man, spoiled because now when I think of my father I see his last weeks filled with pain and hurt in a hospital. Hospitals should be places where the sick receive all the help they need. I see my father pleading for help and painkillers which I could get from the chemist quicker than my father got them. It seemed to us that there was a general acceptance that the elderly suffer. My father would have died maybe in a few years but he did not have to die as he did, in pain. To see someone who has done so much for you in so much need without being able to help is heartbreaking.

In February last year my father had a stroke and was admitted to Kings College Hospital. The emergency care he received was excellent but when he was moved to the wards my father's general care and wellbeing started to decline. There were many different incidents. I began keeping a diary as I wanted to remember what was happening and what we were being told. My journal does not make for nice reading.

Dad was put onto a special mechanical mattress to try and stop him getting bed sores but it was broken. It constantly made a high pitch buzzing sound that was disturbing other patients so nurses kept turning it off. It took days for a new one to arrive and when one did finally come it sat outside in the corridor until they brought a sling to lift and move dad with.

One time he was taken to X-Ray by an orderly but then the orderly left him there, waiting, on his own, in the corridor. It was 8.30pm I went with him and the orderly. The orderly was to bring him back but went home and left him. He said he had been very confused, not sure who to ask somebody to take him back. Then he was left outside his room for 3 hours because they didn't have the sling to transfer him onto the bed. A nurse brought him blankets as it was cold.

Dad eventually went home in April last year. Our family felt at the time he had been sent home too early, he couldn't walk or swallow and he couldn't talk properly. But we were told we would have help, particularly for my mother. But, when the help arrived, they said they were not allowed help with the feeds, as they were not trained to do so. My mum and sister had to figure it out for themselves. I was proud of them it was a hard job, they did well.

Dad stayed at home until November, but was readmitted to hospital on 9th November 2009 as he was bleeding from the areas where the tube was inserted into his stomach for his feeds. I arrived at the hospital at 6.40pm and my mum had been there since 5.00pm. She said from when he came in dad had been saying he was in pain and she had been asking for some pain relief for him. I went and asked as well but I had to ask again at 7.30 and it wasn't until 8.45pm that the medication was given. That is almost 4 hours waiting for pain killers in a hospital. This poor treatment continued throughout my fathers stay in hospital.

When I arrived at the hospital the next evening I found Mum in tears and she left shortly afterward, she couldn't face being there any longer with Dad in pain and them not being given pain relief. They

had been telling mum they would get him some stronger pain killers but they just never arrived as Dad was screaming in pain. After she had left they did come and give him some codeine. I noticed the call bell had been taken away, put where he couldn't use it. Dad told me that all through the night he had been in pain, he was supposed to get pain relief every four hours. He had pressed the call bell and no one came. The man in the bed next to Dad went out of his way to tell me this had happened, he was clearly worried about dad. I worry for the other patients, Dad had all of us and we had such a hard time trying to get dad help I worry for the others who have no one.

When the nurses did give Dad codeine it did not have much of an effect on his pain. I then spent the next few hours asking for them to give him something stronger and the nurses said they couldn't without getting a doctor. They said they had called a doctor but they couldn't say when the doctor would arrive. Dad was pleading with me again and again to help, he needed pain relief, it was incredibly distressing. At one point we were told a doctor was on their way but then they called at 8.45pm to say they couldn't come and we would have to wait longer. The doctor finally arrived an hour later at 9.45pm. The Doctor said the nurses could've given a stronger dose of codeine and then they argued over whether or not they could've done that. He prescribed some oromorph but even then it took another 25 minutes before he was actually given it. This was a very bad night
The next day Dad had a procedure to try and stop the bleeding from his stomach, sealing off the ulcers he had developed. He needed a blood transfusion and was very unwell. Twice they needed to resuscitate him. The doctors asked us if his heart stopped again if we wanted him to be resuscitated again and we agreed this wouldn't be what he wanted.

That evening when we left one of the nurses reassured mum that they would look after him and Mum thanked her. When we came back the next day we found that hadn't happened.
When Mum came in the next day we found out that Dad's window had been left open during the night without a curtain. That night weather warnings had been issued because of gale force winds and freezing temperatures. But Dad had been left exposed to this until 3am in the morning when apparently someone finally came and shut the window. Another patient told Mum how Dad had pressed his buzzer and when that didn't work he had pressed his but that still didn't work so he had gone to the nurses station after waiting and waiting and demanded they close the window. When they came they gave him extra blankets to try and warm him up. This was on a day he had had a procedure done and was very unwell. How was he expected to recover or not get worse when he was left to get freezing cold at night? He developed pneumonia shortly after and I will always wonder whether he would have got it had he not been left like this. This was written on the death certificate but when we first asked about it we were told no, he didn't have it. Very little food, water and care and still my father fought for life. My father wanted to live. The hospital was the only ones who could not see this.

During the day Mum said they had brought pain medicines but didn't give them straight away because they needed to be crushed to go into the tube. For some reason they gave out the rest of the medicines before coming back to do this. They brought fluids and hung them by his bed as if he was due to have them but they never connected them. They didn't come to turn him regularly. The next day was much the same and when I tried to find a nurse I wandered the ward and could only find a first year nursing student.

It continued like this for the next few days. His medicine was delayed, he wasn't being fed through his tube, he wasn't getting fluids. When he was moved to a side room we had to go and complain for them to reconnect his fluids. I was never sure if Dad was getting them or not.

Dad died on the 18th November 2009. On the day he died has was prescribed a morphine pump for his pain by the palliative care team. They visited at noon but the pump wasn't connected until 5.30pm. We were told that it takes time.

We complained to the hospital about his care and had a meeting. They said the records showed he had received some of the things we said he didn't have but they also said they had been concerned about the standard of nursing care over the weekend. We do not think everything written in the records is accurate.

They showed us the record for when the dietician had visited and written instructions for Dad to be given food again through his tube at 100ml over 20 hours, when we had seen them give it to him at 100ml over an hour. We explained to the nurses at the time but they said they were not told to start it slowly. We had learnt from when Dad had been at home for a while when he was discharged not to give food too quickly as it can irritate his stomach. That was the same day he had become unwell and had to have the procedure for his stomach ulcers. They said the two things weren't related but obviously we are left feeling very suspicious.

They explained how sometimes they had restricted his fluid to stop it building up on his lungs but this was never explained to us when we were asking constantly for him to get some fluid.
They apologised for the delay in setting up his morphine pump on the day he died and said it had been reported as an adverse incident. But, when you have seen so much go wrong and tried so hard to get things done properly, it is hard to accept an apology. This was the last few hours of my Dad's life.

They agreed that the nursing care had been unacceptable and assured us our complaint and account would be used for training. I am sorry to say that we are not reassured that this will happen. I wouldn't be confident if someone else I cared for went into the hospital.

17. Robert Henry Bramley

By his daughters Kim Denman and Jayne Johnson

Our father Robert Bramley – Bob – to his family and friends was a fit, healthy, independent older adult who had a full social and family life and was still working in the building industry. He then went into The Kings Mill Hospital in January 2010 with, as one of the consultants caring for him described, "a simple case of diarrhoea".

In April 2010 he left hospital doubly incontinent, paralysed, with grade 2 and 3 pressure ulcers, in pain from his extremely contracted legs, depressed and a facing the prospect of a poor quality of life.

After being discharged in April, my sister nursed him at home with some support until she could not continue. We then were able to settle him into a nursing home where he died in August this year.

On the 18th of January 2010 our Father was admitted to Kings Mill Hospital via the A and E department following severe diarrhoea and low blood pressure. He went onto Ward 52 under the care of a consultant in Health Care of the Older Person.

On the 19th of January, he under went several invasive tests to try to establish a cause of the diarrhoea. My sister Jayne was with him. On his return to the ward an Agency nurse gave him an injection into his stomach, without washing her hands, using antibacterial gel or wearing gloves. As the wound site bled, she swabbed the site with the dirty gown that our father was still wearing following the invasive procedure. My sister reported this and was told that the nurse would not work on ward 52 again, but we do not know if this happened.

The consultant then wanted him transferred onto a Gastroenterology ward. At the end of January, he was transferred to Ward 33 under the care of a gastroenterology consultant. This is when the treatment he received became, in our opinion, what can only be described as appalling neglect.

On February 21st Dad sustained a head injury to the right side of his forehead.

We were given three different accounts of how this happened by three different members of staff. Which account is true we have no idea. They claim that when he was eventually found (their words) a Doctor examined him.

One nurse told us Dad fell forward onto either the table or T.V from his chair. Another nurse said Dad fell hitting his head on the floor near his bed whilst trying to go to the toilet, but he could not walk unaided at this time. And finally another nurse said Dad was found three metres away from his bed near the toilet door and he suffered an impact with the floor. This was the version reported to the Dr that examined him. This Dr went with me to look for records of the incident but none could be found at the time.

On the 21st of February Dad was given no evening meal or drink as it was left out of his reach on a table 2 metres away from his bed. Now he had become bed bound, and was becoming weaker. We were worried this would make him more vulnerable to infection. Not being given food and drink became commonplace. The nursing staff were supposed to be monitoring Dad's food and fluid

intake for the gastroenterology consultant to aid him in his diagnosis. We can only speculate as to what was recorded for him, at best the records were inaccurate at worse false. We complained to the Ward Leader who said that she would look into things. Over quite a few months we only witnessed our Father being fed once and that was when they were expecting us on the ward to see the ward Leader.

After looking into things the Ward Leader concluded that it was catering services that were at fault. We were under the impression that feeding vulnerable bed-bound patients was a caring/nursing role, one that they neglected to do and take responsibility for.

By May after we had complained things improved slightly, but we should never have had to complain about something as basic as this in the first place.

Our Father's room was often untidy and dirty, urine bottles and used, soiled dressings were left on the bedside table where he was supposed to eat. He was left for long periods in soiled bedding and clothing. The Ward Leader did not seem to be bothered or surprised at our complaints about this, it was almost as if she expected this practice, as the standard that she accepted from her staff.

During March, our Father suffered several infections including MRSA. We also noticed his legs becoming increasingly contracted and painful, but our pleas for help were not listened to. It was assumed his poor mobility was because of diarrhoea and general weakness. If he couldn't get out of bed to take part in exercises no passive physiotherapy was given. At this point Dad became depressed because he knew that he was becoming increasingly ill totally bed –bound and dependant. No help was offered or given for the depression at this time.

One of the most worrying incidents during Dad's stay happened during this time. My nephews were visiting one evening in March when a care assistant went into the room and Dad asked her to move him up the bed. In front of them, she grabbed him by his neck and hauled him up into a more sitting position. She did not ask a colleague for help, she did not use a slide sheet or take any notice of his medical history that would have told her that he had broken the top two vertebras in his neck 5 years earlier.

Our Father was in severe pain but it did not stop her nor did the alarm expressed by my nephews. We complained about this incident to the Nurse in charge but the next day whilst I was visiting the healthcare assistant came into Dads room and challenged him about getting her into trouble. His response was "I don't get people into trouble, they get themselves into trouble when they don't do their jobs properly".

I could not believe that she was still on the ward, when my sister arrived we went to speak with her she turned as she saw us and disappeared into staff only area. The ward Leaders action was to send her for handling training, no discipline action was taken. Our witnesses were not spoken to by the ward. At this point we were so alarmed that we contacted Social Services and made Dad a safeguarding issue. The Hospital were not pleased with us, communication became even more difficult and we worried about what was happening to Dad when we were not there. As it unfortunately proved, we were right to be alarmed.

During March, his condition become worse he contracted several infections all of which made him weaker and more depressed. As a family we were under a great deal of stress asking for help but

feeling ignored, seeing what we considered neglect and abuse and watching our Father deteriorate before us.

He became very confused and disoriented as each infection took hold. However, he had amazing inner strength and some how he managed to come through. He told me one evening "they will not beat me you know", I cried all the way home, and it was obvious that at some point even he would not be able to fight back.

I think the general attitude of the Doctors, nurses and carers on ward 33 was incredibly unprofessional in their care, hygiene practises, basic nursing skills, communication skills and most painful of all their inability in simply offering human kindness to another human being who was very poorly. We naively thought that these were traits that should be found in any healthcare professional.

On the 8th of April Dad was moved back onto Ward 52 for rehabilitation, we still had no diagnosis for the bowel problem. The gastroenterologist had tried but failed before he moved to another ward and another gastroenterologist took over. He told us that they were looking for the rare but some tests were outstanding and we would be informed of the outcome later. We still have no conclusions from these tests and no diagnosis. Both he and the consultant Dad was admitted under now felt that the way forwards was to give Dad rehabilitation on Ward 52.

On the evening that Dad arrived on Ward 52, I met the Ward Leader who was shocked at his condition in particular his contracted legs. She contacted an excellent Neurologist and a fine human being. Within a couple of days he had a very good idea of Dads condition regarding his contracted legs. Tragically he thought it was some kind of viral infection that caused irreparable damage to both the nerves and nerve coatings in his legs causing paralysis.

He wanted to take Dad to the Neurological Labs at the Queens Medical Centre Nottingham to run tests to confirm his ideas and to find out if he could offer any treatment. It took Ward 52 three attempts at arranging transport for these tests to take place. Each time neurologist had his team waiting, Dad had been dressed and prepared to make the appointment with a care assistant to go with him yet, a simple matter of booking an ambulance proved to be far too much for them to arrange. The Ward just blamed Queens Medical Centre, the Ambulance service/crew, anyone but them. Eventually on the third attempt, Dad went to Queens.

A couple of days later I met the neurologist on the Ward with my Dad as he told him the devastating news that the damage to his nerves was too great and that he would never walk again. He was very sensitive as he delivered this terrible news. He told me at this time that if he had been called earlier the damage may not have been so extensive and that they could see the viral damage during the tests. He said "it is like all things of this nature early diagnosis and intervention are key". We feel that Ward 33 neglected Dads contracting legs despite our us raising concerns to such an extent they they caused him to become paralysed and this might have been avoided.

At this point Dad became even more depressed. My sister went to see the consultant for older people who was now looking after him again to discuss Dads depression. His response was to ask, "What makes you think he is depressed". Perhaps the crying all the time, the strange dreams and

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threats of suicide should have given him a bit of a clue as to our Dads state of mind. As my sister works in mental health and given the fact that the consultant was clearly not going to do anything about Dad's mental health she contacted a Mental Health Nurse. She went to visit with our Father and he was put on medication for depression. The Ward didn't seem to like this at all but we had to get him help because they were just neglecting to his difficulties.

Following the diagnosis from the neurologist our Father was very upset by a wicked comment made to him by the Consultant for older people. On a ward round in front of a group of medical students he said to him and I quote, tapping on Dads bed "you will need one of these hospital beds when you go home and you will never (pointing to his legs) use these again". How can any responsible professional make such an awful comment to an already depressed poorly man, we feel that this was verbal abuse.

On April 8th, I had arranged through the nursing staff to see this consultant between 2 – 4pm during his rounds. We arrived on the ward and he was told. At 4:15, we left the ward because he had gone without keeping our appointment, another example of poor professionalism.

My sister met with Ward 52 leader to discuss the verbal abuse that our Father had received from some of her night staff. They were made to apologise for telling him to stop messing himself and accused him of "playing" in his own mess. This is verbal abuse and bullying of the most hideous nature.

On the 22nd of April the consultant demanded that we attend a discharge meeting because apparently our Father was now medically fit to go home. We were very alarmed by this as our Father was now much more poorly than when he was admitted, we could not understand the logic. A social worker and occupational Therapist were also summoned to this meeting at 2pm. We all attended at 2pm but the consultant went on ward rounds and kept us waiting until 4:15 at which point my sister went to find him and he said he was busy and that the social worker would sort the discharge out anyway. The other professionals attending had to leave before us.

Our Father was discharged on the 28th of April, which put us under tremendous pressure to get everything ready for him to come home. An occupational Therapist went to Dads home to assess it, and decided that it would be appropriate for him to live downstairs with a screen around his bed, with no bathroom down stairs and one kitchen sink to care for all his needs. This meant food preparation, washing him, cleaning equipment was safe in her opinion to be carried out in this one space. My sister who had moved in to look after Dad had to fight to get this ludicrous and dangerous situation changed, and have Dads bed taken upstairs.

When he came home, he arrived wearing only a filthy vest that was not his despite us having taken clothing in for him to travel home in. We could not believe the indignity of it, and Dad was very upset by it. He arrived home without any medical notes for the District nurses and carers and without a district Nurse referral in place. The ambulance crew were rude to my sister because they had to take him up stairs and that he had eight bags of belongings. He came home without the appropriate resources to care for him, no incontinent wear, and no catheter care I had to phone the hospital to ask for them. They then had the affront to ask me to go and collect them, the resources came by Taxi.

The discharge was dangerous and rushed. When the carers arrived later on the day of discharge they were appalled by Dads poor hygiene, they had never seen a person so poorly looked after. They cleaned congealed body fluids, creams etc. from around his genitals which were red, sore and infected. He also had grade 2 and 3 pressure ulcers that were not dressed correctly either; this is how Kings Mill discharged our Father.

My sister next had a visit from the same Occupational Therapist assessing for a stair lift to be fitted for a patient with bowel cancer. This was incorrect and wrongly recorded, as Dad did not have the condition. The hospital now admits this was an incorrect diagnosis.

Robert Henry Bramley died in a Nursing home in August from heart failure following a chest infection. Our family have been to hell and back this year through what we can only describe as neglect and abuse metered out by Kings Mill Hospital. My sister took time off from her work to care for our Father, which was so difficult that it made her ill. Dad needed 24 hour-a-day care and although she had excellent support from both the district Nurses and Care UK it was simply too much. My sister had to take time off work to recover but, even now after losing our Father in August, she does not have the strength to help write this letter. However, we support each other by sharing the burden and I do the writing. The effects on our family have been very distressing. Dad's grandchildren miss him and believe that if Kings Mill had have treated him correctly that he would still be with us. We agree. This shoddy inhumane practise cannot carry on, we promised Dad that we would fight on because in his words "what about the people who do not have a voice". We made him a promise to do so, as even at the very end of his life he was concerned that no one else should suffer the pain and neglect that he had endured in your hands.

We have complained and written a number of letters to the Trust, the process is still ongoing. But the responses we have received already have made us even more concerned as they are often inconsistent.

We had a meeting on the 8th July whilst Dad was still alive and discussed the issues. The Trust said they would send a full response within 28 days. It took almost 3 months, and of course by then our father had died.

Responding to our question as to why Dad had diarrhoea the Trust said it was related to the nerve damage. The neurologist explained to us at the time this was not the case.

They say they won't ever use the agency nurse again that wiped her hands with dads clothes, but where else is she going to work? Surely they should make sure the agency investigate this.

They insist that Dad was not discharged with pressure sores but cannot explain why the district nurses who looked after him when he got home said they were present. They say the discharge notes are clear there weren't pressure sores. These are the same notes that apparently say he was turned all the time and so you can imagine how much faith we place in them.

They cannot explain how the referral to community services was lost, but say the staff member has been retrained.

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They admit it was unacceptable for the nurse who handled my dad so poorly to confront my dad about the fact he had complained, but they don't give an explanation as to what action they will take.

They say he was referred to physiotherapy and say assistance was offered. But there is a huge difference between an offer being made and consistent and appropriate treatment-taking place. This simply did not happen; varieties of excuses were given, for the intermittent physiotherapy, none of it helped our father.

In fact the Consultant that apparently investigated our complaints is someone our family have never heard of, but no explanation was given as to who he is, what he has done and why he was asked to look into things. They just write about this Consultant in the letter, no introduction.

Trust Responses

1. Peggy May Wood - Southend University Hospital NHS Foundation Trust

Mr Rakesh Vasishtha, head of communications and marketing:

"We are grateful for the feedback we received from Mrs Styles and confirm that we responded to her concerns on two separate occasions (6th May 2009 and 11th February 2010). The issues highlighted were also raised within the Trust and we are sorry for the distress that was caused."

2. Anne Robson - West Suffolk Hospital NHS Trust

We would like to take this opportunity to once again extend our sincere condolences to Mrs Robson's family.

We are sorry that Mrs Pryor feels the care her mother received fell below the high standards we would expect. We have met with her family on two occasions so that we could discuss their concerns in more detail and answer any questions they had. In addition, we have fully investigated Mrs Pryor's initial complaint and fed back the results to the family.

We want everybody who uses West Suffolk Hospital to have a positive experience of the care we offer. As such, we encourage feedback from patients, families and carers as it helps us build on good practice already in place as well as highlighting areas where we could improve further and the action we need to take.

3. Elsie Poague - Epsom and St. Helier University Hospitals NHS Trust

Chief Executive Samantha Jones said: "I am genuinely sorry that Mrs Mistry is unhappy with the care we gave to her aunt, Mrs Elsie Poague.

"I expect our doctors, nurses and other staff to provide each and every patient with the best possible care and to treat them as if they were a member of their own family.

"Whilst we have not had a formal complaint from Mrs Poague or her niece, I have personally contacted Mrs Mistry and have asked to meet with her so that I can better understand her concerns and make sure we learn from them."

4. Brigid Wainwright - Plymouth Hospitals NHS Trust

Sarah Watson-Fisher, Chief Nurse for Plymouth Hospitals NHS Trust, said: "I am extremely sorry that Mrs Wainwright was unhappy with the standard of care she received whilst in hospital. I would welcome the opportunity to investigate Mrs Wainwright's concerns regarding her own care and would encourage her to make contact with the Trust so that we can carry out a thorough investigation.
"It is regrettable Mrs Wainwright felt unable to raise the issues at the time, as her concerns could have been readily remedied by the Matron and Ward Manager and appropriate action taken.

"I am sorry Mrs Wainwright felt that nursing staff offered insufficient care and attention to her specific needs. Every effort is made to try and help patients get comfortable, feel settled and know how to call for help from the nursing staff if needed.

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“It would not be possible nor appropriate for us to comment about particular concerns regarding other patients' care. However, I wish to offer assurance that each patient on our wards has an appropriate care plan to support their treatment.

“I would like to reiterate the offer to meet with Mrs Wainwright and investigate her concerns.”

5. Francesco Barsciglie - Royal Devon and Exeter NHS Foundation Trust

RD&E Director of Nursing and Patient Care Em Wilkinson-Brice said: “Mr Franco Barsciglie received treatment at our hospital regularly over a number of years and he was well known by our haemodialysis service staff who were very saddened by his death. We sincerely regret that Ms Clarke was not with her husband when he passed away but Mr Barsciglie’s death was unexpected and could not have been anticipated by our ward team who checked and cared for him throughout the night. We believe we have addressed the issues Ms Clarke raised and hope from our detailed explanation that Ms Clarke can be reassured that the clinical care Mr Barsciglie received was appropriate. We acknowledge that lessons have been learnt regarding improving communication with relatives, and changes have been made, for example offering accommodation arrangements for relatives of patients not critically ill but who are potentially unstable, if they would like to stay on the ward or on the hospital site.”

6. David Perkins - Southend University Hospital NHS Foundation Trust

Mr Rakesh Vasishtha, head of communications and marketing:

"Mrs Perkin's complaint is being investigated in line with NHS procedure. We anticipate sending a full response in the near future. Meanwhile the Trust can be contacted directly if Mrs Perkins wishes to do so."

7. Jean Kellard - Leeds Teaching Hospitals NHS Trust

Response from Ruth Holt, Chief Nurse, Leeds Teaching Hospitals NHS Trust:

“Mrs Brown contacted the Leeds Teaching Hospitals through our Complaints Office, and we tried very hard to respond to her concerns in a factual and constructive manner.

“We are therefore very sorry to hear Mrs Brown felt unhappy with our response, as she did not contact us again to say so. We have offered to meet her on a number of occasions and remain happy to do so if it would help resolve her concerns.

“We are always happy to look into matters further if individuals feel they need more reassurance and do try very hard to resolve complaints to the satisfaction of all concerned and learn lessons when mistakes have been made.

“In a letter Mrs Brown received from us in May following an investigation undertaken by one of our consultants and the matron for medical services, we acknowledged that the care and communication Mrs Brown’s mother and her family received from the Leeds Teaching Hospitals was not of the standard we would expect to deliver.

"We sincerely apologised for this and went into some detail to a number of points regarding specific issues Mrs Brown's family raised. We do not feel it is appropriate to share every aspect of our response in a public forum, but we believe we did address all her concerns in an open and clear way.

"This included listing actions we have taken to ensure this was discussed with the staff involved and more generally what has been done to improve communications with patients and their families in this part of the hospital.

"We have used elements of Mrs Brown's story in staff training and development to help us to improve the care we give. The patient experience forms an integral part of how the Trust develops and assures the quality and safety of patient care."

8. Muriel Browning- Ipswich Hospital NHS Trust

We investigate every concern raised by patients and their relatives very thoroughly. We are sorry that this relative has had an unhappy experience. There are always different perspectives and in this particular instance, we do not recognise or agree with the relative's perspective.

9. Louise Jacob Mid Essex Hospital Services NHS Trust

We would like to offer our sincere condolences to the family of Mrs Jacob. The Chief Executive has apologised to Mrs. Jacob's daughters for the distress caused to them in relation to the care of their mother.

We have received a formal complaint from Mrs. Jacob's daughters and have completed a full investigation into the concerns raised by them surrounding the care of their late mother. We hope that we have been able to address their concerns fully as a result of our investigation, and we have reassured the family that we have taken their concerns seriously. We have found that sometimes families find it helpful to meet with the appropriate senior members of staff to discuss their concerns and we have offered Mrs Jacob's daughters the opportunity to do this.

10. Megan Davis - Gloucestershire Hospitals NHS Foundation Trust

Dr Frank Harsent, Chief Executive of Gloucestershire Hospitals NHS Foundation Trust said:

"We were very sorry to read about the experiences of Mrs Davis whilst in our care last year, and offer our sincere condolences to her family.

"Some of these concerns were raised in a letter to the Trust written by Mrs Davis' daughter earlier this year, to which we responded, offering to investigate them fully. The full details including Mrs Davis' name were not provided, which meant that the Trust was unable to move forward with an investigation at that time.

"However, the general areas of concern raised by Mrs Davis' daughter have influenced improvements in services on surgical wards and informed our patient experience strategy.

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"We take issues such as these very seriously and investigate them thoroughly when they are raised with us. Now we are aware of the patient's identity, we will be investigating all aspects of her care in order to learn and to improve the care of patients overall.

"The Trust is committed to protecting the dignity and safety of patients, and involving families in the care of their patients. When issues are raised and investigated we ensure that staff learn from them and that we change our ways of working where this is necessary.

"We will also be making contact again with Mrs Davis' family in order to have the opportunity to talk face-to-face with them about their concerns."

11. Patient A - ABM University Health Board

ABM University Health Board takes quality and safety extremely seriously and strives to provide the best possible care for all our patients. We are very sorry that in this instance we failed to achieve the standards of care we should be delivering.

Following receipt of a letter of complaint from the patient's family, regarding care received at Maesgwyn Hospital, a full investigation was undertaken. As a result of this investigation significant changes have been made to ensure that at all times we are fully meeting the needs of our patients, who are very often frail and vulnerable. The role of the Ward Sister has been revisited to provide a clear focus on overseeing the care being delivered and to ensure standards are maintained. A robust education and training programme has also been implemented for Ward staff.

The account of care does contain elements relating to the Health Board that were not included within the original letter of complaint. In order to ensure that all possible lessons can be learnt from this, the additional areas highlighted will now be investigated and the Health Board will make contact with the patient's next of kin accordingly.

Again, we wish to apologise to the patient and her family and would like to take this opportunity to reassure them that the Health Board has, and will, continue to ensure the standards of care delivered within these areas are monitored closely.

12. Joan Louise Hilleard- South London Healthcare NHS Trust

No response received.

13. Elizabeth Cavanagh - Barking, Havering & Redbridge Hospitals NHS Trust

We have offered our sincere condolences to Mrs Dowsett following the death of her mother, and have tried to address the concerns that she has.

The Trust works hard to continually improve patient care and patient experience.

Within the last few months we have introduced a range of new initiatives including a visible leadership programme – which sees all of our senior nurses, including the Director of Nursing, back in uniform and back on the wards.

We have also started Patient Safety walkrounds with the executive team visiting all of our clinical areas, and successfully implemented a new system for ensuring that all patients who need help with feeding themselves receive the assistance they need.

Patient care is at the heart of everything we do and we are keen to meet with Mrs Dowsett to talk through any issues she may have.

14. Albert George Edwin Battey - South London Healthcare NHS Trust

No response received

15. Irene Schneider-NHS Devon

Ann James, chief executive, of NHS Devon, said.: "I would like again to offer our sincere condolences to Mrs Schneider's family. Following contact from the Patients Association I would also like to reiterate how sorry I was to learn of the problems experienced.

"On review it has become clear that we made a mistake. The document provided to us was in fact a Notice of Registration of Lasting Power of Attorney (LPA) Personal Welfare – and not, as we had previously indicated, a request for the document.

"I know that the mistake has caused Mr Yeo some degree of distress and I am genuinely sorry for this.

"I spoke with Mr Yeo on the telephone this afternoon (TUE).

"I listened to his concerns about how his mother-in-law was cared for and discussed how the complaint had been handled so far. I apologised to him after hearing his story.

"As a consequence of this conversation, and with Mr Yeo's full agreement, we are instituting a review of the clinical care Mrs Schneider received.

"We will also review the handling of the subsequent complaint so this does not happen to other people in Mr Yeo's position again.

"The reviews will be independent of NHS Devon and aim to demonstrate our commitment to change the way complaints of this nature are dealt with in future.

"Mr Yeo will be kept fully informed of the progress of the review."

Royal Devon & Exeter NHS Foundation Trust

Director of Nursing & Patient Care at the Royal Devon & Exeter Em Wilkinson-Brice said:

"We are very pleased that Mr Yeo did what we encourage our patients and visitors to do, which is to raise a concern at the time so that we are able to resolve any issues promptly. Our understanding is that Mr Yeo on both the occasions he raised concerns was satisfied with the outcome and decided not to take the matter further."

16. Stefan Jedrzejczak – Kings College Hospital NHS Foundation Trust

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We would like to extend our sincere condolences once again to Mr Jedrzecjzak's family for their loss. We received a formal complaint from Ms Jedrzecjzak about the care her husband received at King's prior to his death in April this year. We convened a meeting with the family and members of the clinical service that cared for her husband to discuss their concerns further. After investigating Ms Jedrzecjzak's complaint, it was clear that specific aspects of the nursing care and pain management her husband received during part of his stay at King's fell short of the high standards we set ourselves. The ward on which Mr Jedrzecjzak was cared for consistently delivers a high standard of care for its patients, so we were surprised and disappointed to learn of the family's concerns. We would like to apologise again to Mr Jedrzecjzak's family for this. The feedback from his family has been used by the senior nursing team in question during staff development and training. As a result, we hope this goes some way to reassuring Mr Jedrzecjzak's family that we take these concerns seriously, and have taken preventative action to ensure the same thing doesn't happen again. Finally, we would like to reassure all patients and their relatives that we take the safety and well-being of our patients extremely seriously. It is also important to state that we make every effort to ensure feedback from patients and their families is used to improve the service we provide.

17. Robert Henry Bramley -Sherwood Forest Hospitals NHS Foundation Trust

Statement: This case is part of a formal complaints procedure therefore Sherwood Forest Hospitals NHS Foundation Trust are unable to comment.